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14		
15		
13	UNITED STATES D	ISTRICT COURT
16	NORTHERN PARTNER OF GALVE	SORVIA OLIVIAND DIVIGIONI
17	NORTHERN DISTRICT OF CALIF	ORNIA, OAKLAND DIVISION
1 /	STACIA STINER, et al., on behalf of themselves	Case No. 4:17-cv-03962-HSG (LB)
18	and all others similarly situated,	` ′
19	Plaintiffs,	DECLARATION OF JUNE
19	V.	ISAACSON KAILES IN SUPPORT OF PLAINTIFFS' MOTION FOR
20	BROOKDALE SENIOR LIVING, INC.;	CLASS CERTIFICATION
. 1	BROOKDALE SENIOR LIVING, INC.,	
21	COMMUNITIES, INC., et al.,	Date: May 26, 2021
22		Time: 2:00 p.m.
	Defendants.	Place: Courtroom 2
23	Bolondants.	Judge: Hon. Haywood S. Gilliam, Jr.
24		
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28		

Case No. 4:17-cv-03962-HSG (LB)

DECL. OF JUNE KAILES IN SUPPORT OF PLAINTIFFS' MOTION FOR CLASS CERTIFICATION
Doc ID: f021b518546cb645b3adebbf0264a5e4e91fb140

I, June Isaacson Kailes, declare:

- 1. I have personal knowledge of the matters set forth herein, and if called as a witness, I could and would competently so testify. I make this declaration in support of Plaintiffs' Motion For Class Certification.
- 2. I hold a Bachelor's degree in Psychology from Hofstra University and a Master's degree in social work from the University of Southern California. Since 1985, I have worked as a disability policy consultant and trainer for government entities, universities, businesses, and nonprofit organizations. One of the topics on which I offer consulting and training services is related to integrating access and functional needs into emergency planning, response, and recovery.
- 3. I served as the Associate Director of the Harris Family Center for Disability and Health Policy at Western University of the Health Sciences in Pomona, California from November of 2002 through March of 2018. At the Harris Family Center for Disability and Health Policy, I managed disaster preparedness projects, supervise staff, taught courses to health professionals, and oversaw and participated in research regarding health care and emergency management related to people with disabilities.
- 4. In 1995, President Clinton appointed me to serve on the Architectural and Transportation Barriers Compliance Board ("Access Board"), the national regulatory body that sets standards for ensuring the accessibility of the built environment. Some of the areas in which I focused while on the Access Board were access to telecommunications and passenger transportation, as well as revising and updating the Americans with Disabilities Act Accessibility Guidelines (ADAAG).
- 5. I spent twelve years working for the Westside Center for Independent Living in Los Angeles, first as Programs Director and then, from 1981 to 1989, as Executive Director. Under my leadership, the Westside Center for Independent Living was named one of the top five independent living centers in the nation.
- 6. I have served on numerous boards and committees, State Emergency Management Systems, mass care and shelter, and training and exercise committees of the California Emergency

Management Agency. I have developed and led workshops and taught university courses throughout the country and internationally on such topics as the Americans with Disabilities Act (ADA), assistive technology, emergency planning and preparedness for people with disabilities, and integrating access and functional needs into emergency planning, response, and recovery.

- 7. I have participated on several national task forces regarding disaster planning and response for people with disabilities, including the Consortium of Citizens with Disabilities Emergency Management Task Force (2007-2009), the National Fire Protection Association Center for High Risk Outreach Fire Safety for People with Disabilities Task Force (2004-2015) and the U.D. Department of Homeland Security's National Response Plan Special Needs Work Group (2006-2007). I was appointed to the Federal Emergency Management Agency's ("FEMA") National Advisory Council and served in that capacity from 2010 through June 2019.
- 8. I have presented trainings on emergency preparedness issues for people with disabilities in Turkey and Japan, as well as throughout the United States, to diverse audiences including people with disabilities, community-based organizations serving people with disabilities, emergency managers and planners, the American Red Cross, and first responders including paramedics. Through the California Emergency Management Agency, I have co-taught workshops with state personnel and the American Red Cross on the Functional Assessment Service Team ("FAST") concept in counties throughout the state. The concept of FAST is that governmental and nongovernmental organization employees with expertise in the diverse population of people with disabilities and other functional needs can be deployed to shelters to identify problems and provide shelter residents with needed equipment or support in maintaining their health, safety and independence. FASTs are force multipliers that can extend the reach of emergency managers in response and recovery capacity by supplementing the knowledge and experience of traditional government emergency responders.
- 9. From 2008-2010, I was a member of the group responsible for reviewing and revising California's state emergency plan. I have also been engaged as a consultant by various local governments to assess their existing plans, conduct gap analyses to determine where the needs of disability communities were not being adequately addressed, and to otherwise assist

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in their emergency planning and training processes. Some of these clients have included the City of Oakland; the City of San Diego; Kern County, California; Riverside County, California; San Bernardino County, California; Office of the Governor, Hyogo Prefectural Government, Japan; Clark County, Washington; and the Commonwealth of Virginia.

- 10. I have authored numerous publications on the topic of emergency planning and response for people with disabilities, from individual preparedness guides for people with disabilities and others with access and functional needs to reports on lessons documented from specific disasters. One landmark article widely used is Kailes, J. I. and Enders, A. (2007) Moving Beyond "Special Needs": A function-based framework for emergency management and planning, Journal of Disability Policy Studies, 2007. 17: p. 230-237. Other key publications in this area have been: Kailes, J. (2002) Evacuation Preparedness: Taking Responsibility For Your Safety: A Guide For People With Disabilities and Other Activity Limitations, http://www.jik.com/pubs/EmergencyEvacuation.pdf; Kailes, J. (2009) Emergency Power Planning for People Who Use Electricity and Battery Dependent Assistive Technology and Medical Devices, http://www.jik.com/Power%20Planning%2010.24.09.pdf; Stough, L. M., & Kailes, J. I. (2010) "Disabilities and Disaster", In K. B. Penuel, M. Statler, J. G. Golson (eds). Encyclopedia of Disaster Relief (pp. 109-110), Thousand Oaks, CA: SAG; Kailes, J. and Enders, A. (2014) Access and Functional Needs Emergency Registry Assessment Tool, http://www.jik.com/d-rgt.html; and Kailes, J. (2014) Checklist for Integrating People with Disabilities and Others with Access and Functional Needs Into Emergency Preparedness, Planning, Response & Recovery, http://www.jik.com/plancklst.pdf. I also researched and drafted the 2005 report entitled "Saving Lives: Including People with Disabilities in Emergency Planning" under contract with the National Council on Disability and was part of the analytical and writing team that prepared the Report on the Special Needs Assessment for Katrina Evacuees Project for
- 11. One of my contributions to the emergency management field has been the development of the "functional needs" approach to planning. I developed this concept because the traditional definition of "special needs populations" was too narrow in that it focused only on

the National Organization on Disability in 2005.

people with certain labels or diagnoses (*e.g.*, blind, deaf, or wheelchair-users) and too vague in that it did not give any guidance to planners about what specific types of assistance people in these groups would need in an emergency. By contrast, a function-based framework focuses on the functional areas in which people are likely to need help in a disaster – communication, health care, maintaining safety and independence, access to transportation – regardless of whether the people with these needs had pre-existing disabilities, were injured during the disaster, or belong to other groups such as children or older adults. Although everyone has functional needs, the consequences of people with disabilities and activity limitations not receiving needed support can be much more severe and much less forgiving. Since I first developed and began promoting the functional needs concept in a series of articles published in 2005 and 2006, FEMA and the U.S. Department of Homeland Security have adopted it in guidance documents and it has been incorporated into many emergency plans at the federal, state, and local levels.

- 12. I served as an expert witness in *California Foundation for Independent Living Centers v. County of Sacramento*, 142 F. Supp. 3d 1035, 1049 (E.D. Cal. 2015), a case about whether the emergency evacuation plans adopted for Terminal B at the Sacramento International Airport were accessible to and inclusive of people with mobility disabilities. My work in that case involved reviewing the Terminal B evacuation plans to determine whether components of the plans, including advanced planning, actual evaluation, notification and communication, and recovery after evacuation, were accessible to and inclusive of people with mobility disabilities.
- 13. I served as an expert witness in *Communities Actively Living Independent and Free, et al. v. City of Los Angeles*, Case No. CV-09-0287 CBM (RZx) (C.D.Cal.), a case about the emergency needs of people with disabilities in Los Angeles. In that case, I was involved in reviewing a draft Access and Functional Needs Annex for the County of Los Angeles as part of an interim agreement between plaintiffs and the County of Los Angeles. After plaintiffs prevailed on their motion for summary judgment against the City of Los Angeles, I was included in the Court's injunctive relief order to be part of the team of experts tasked with reviewing and revising emergency plans for the City. I was specifically designated by the Court because of my disability expertise.

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- 14. I served as an expert witness in Brooklyn Center for Independence of the Disabled, et al. v. City of New York, Case No. 11-cv-6690 JMF (S.D.N.Y.), a case where plaintiffs prevailed after a trial regarding the adequacy of New York City's emergency plans with respect to the emergency needs of people with disabilities. In that case, I was qualified as an expert at trial. I analyzed New York City's emergency plans and testified at trial regarding the deficiencies I found in the plans with respect to the needs of people with disabilities.
- 15. A true and correct copy of my most recent *curriculum vitae* is attached to this Declaration as Exhibit A.

Consultation in This Matter

- 16. Plaintiffs' counsel have retained me to provide expert analysis in this case about the extent to which the emergency plans in place at Brookdale Senior Living ("Brookdale") facilities provide Brookdale residents who have mobility and/or vision disabilities with access to the emergency programs and services offered by Brookdale on a full and equal basis as residents without mobility and vision disabilities.
- 17. The opinions and conclusions I have reached in this matter are based on all of the following: (1) the evidence I have reviewed regarding Brookdale's emergency evacuation and disaster plans for its California facilities, including the Emergency and Disaster Manuals for 2020, emergency supplements produced for certain facilities in this case, contracts with emergency transportation vendors, and other written Brookdale policies and procedures regarding emergency evacuation and disaster planning; and (2) my background and experience as a specialist in the field of emergency planning for people with disabilities.

Conclusions

18. My analysis of Brookdale's emergency planning documents has revealed serious gaps in planning and many deficiencies with regard to Brookdale's ability to meet the needs of its residents with mobility and/or vision disabilities before and during an evacuation. Specifically, Brookdale's emergency plans are vague, incomplete, and lacking specificity

Case No. 4:17-cv-03962-HSG (LB)

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5	19. Because of the deficiencies in Brookdale's emergency plans, it is my opinion that	
6	residents with mobility and/or vision disabilities face a significant risk of losing their health, their	
7	independence, and even their lives during an evacuation from one of Brookdale's assisted facilities	
8	in California.	
9	20. The risks to residents of senior living facilities during an emergency are very real	
10	given the fact that most residents in assisted living and memory care programs require assistance	
11	with activities of daily living. I understand that many of Brookdale's California facilities have	
12	multiple levels of apartments and common use areas below and above ground level, which	
13	requires that a plan be in place for how to evacuate residents who require assistance to get to the	
14	ground floor. Without a sufficient number of staff specifically trained on how to evacuate	
15	residents with different needs and abilities, there is a heightened risk that residents will not be	
16	evacuated with the speed that emergencies often require.	
17	21. The documents I reviewed related to Brookdale's emergency plans include: (1)	
18	Brookdale's 2020 Emergency Manual; (2) Emergency and Disaster Plans and supplemental	
19	emergency plans for a sample of facilities ¹ and the 2019 California Supplemental Emergency	
20	Manual; (3)	
21	(4) a sample of fire drills conducted and documented; (5) other	
22	miscellaneous policies and forms related to emergency evacuation and planning; ² (6) Plaintiffs'	
23	Third Amended Complaint; and (7) Defendants' Answer to Third Amended Complaint.	
24		
25	¹ These facilities include, <i>inter alia</i> , Sunwest, Corona, Lodi, San Juan Capistrano, Tracy, San Ramon, Napa, Scotts Valley, Fountaingrove, and San Pablo. The plans that I reviewed provided	
26	essentially the same information regarding evacuation plans and procedures.	
27	² These documents include	
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22. Based on my review of these documents, Brookdale's plans for emergency evacuation at its facilities

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People with mobility and/or vision disabilities have specific needs as to each component, which must be accommodated through careful and specific procedures and plans that address their needs. I discuss all of these components below.

Evacuation from Upper Floors

23.

As indicated in the declarations of many of the putative class members submitted with this motion, residents who have mobility and/or vision disabilities often live on the second or third floors of Brookdale facilities. See, e.g., Declaration of Barbara Switzer In Support of Plaintiffs' Motion for Class Certification at ¶ 24; Declaration of Bernice Caan In Support of Plaintiffs' Motion for Class Certification at ¶ 22; Declaration of Charlotte Paulsen In Support of Plaintiffs' Motion for Class Certification at ¶ 21; Declaration of Cory Sheek In Support of Plaintiffs' Motion for Class Certification at ¶ 20; Declaration of Fred Wells In Support of Plaintiffs' Motion for Class Certification at ¶ 21; Declaration of Joshua Levin In Support of Plaintiffs' Motion for Class Certification at ¶ 15; Declaration of Nancy Sage In Support of Plaintiffs' Motion for Class Certification at ¶ 22; Declaration of Nick Jamson In Support of Plaintiffs' Motion for Class Certification at ¶ 24; Declaration of Norma Ribich In Support of Plaintiffs' Motion for Class Certification at ¶ 16; Declaration of Patricia Anne Phelps In Support of Plaintiffs' Motion for Class Certification at ¶ 20; Declaration of Patty Hefner In Support of Plaintiffs' Motion for Class Certification at ¶ 16; Declaration of Paula Fischer In Support of Plaintiffs' Motion for Class Certification at ¶ 18; Declaration of Ray Lombardini In Support of Plaintiffs' Motion for Class Certification at ¶ 17; Declaration of Ray Voorhis In Support of Plaintiffs' Motion for Class Certification at ¶ 18; Declaration of Steve Wright In Support of Plaintiffs' Motion for Class Certification at ¶ 19; Declaration of Yvonne Rons In Support of Plaintiffs' Motion for Class Certification at ¶ 17. People with mobility disabilities may require assistance evacuating stairwells during an emergency when elevators are not in service, which is

1	typicany the case during an emergency. To evacuate a stanwen, many people with modifity
2	disabilities will require the use of an evacuation device, such as a stair chair. These devices are
3	particularly critical and life-saving in multi-level buildings. One example is an evacuation chair
4	which "resembles a large, folding chair with rear wheels that pop up and a sled-like component
5	that takes their place when going down stairs." See Kailes, J.I., Emergency Evacuation
6	Preparedness: Taking Responsibility for Your Safety, at 4,
7	http://www.jik.com/pubs/EmergencyEvacuation.pdf.
8	24. Brookdale's Emergency Manuals are vague and
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13	For example,
14	page 65 of the 2020 Emergency Manual, which discusses the
15	
16	BKD1569794, at 65. This procedure is inadequate because it is
17	vague, nondescript, and incomplete and does not describe the specific way that this will be
18	implemented.
19	
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22	25. The supplemental Emergency and Disaster Plans I reviewed for a sample of
23	facilities were
24	See, e.g., Emergency and Disaster Plan for Brookdale Tracy, BKD1867468;
25	Emergency and Disaster Plan for Brookdale Scotts Valley, BKD2179317. These plans contained
26	but
27	
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1	26. The procedures in Brookdale's 2020 Emergency Manual fail to include any
2	instructions for
3	The Emergency Manual
4	2020 Emergency Manual,
5	BKD1569794, at 65.
6	
7	See Audrey Withers Tr., July 23, 2021, at 130:21-131:20. Similarly, in the records of fire
8	drills that I reviewed, I did not find any instances where staff members had practiced using
9	evacuation chairs or other methods of evacuating residents who require mobility assistance to get
10	up or down stairwells. Instead, it appears that staff are expected to perform these types of
11	procedures "on the fly" during an actual emergency, without the benefit of regular practice. See
12	also Theresa Ward Tr, March 17, 2021, at 224:2-23 (vendor conducting fire drills uses
13	"simulations" but "not actual moving people from point A to point B").
14	Transportation from Evacuated Area
15	27. Brookdale's emergency plans and procedures also fail to ensure that accessible
16	transportation is provided to residents with mobility disabilities. The 2020 Emergency Manual
17	states that
18	2020 Emergency
19	Manual, BKD1569794, at 18. It is unclear whether Brookdale's policies permit non-scooter
20	wheelchair users to bring their wheelchairs during an emergency. Similarly, Brookdale's written
21	policy on states that
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23	28. Forcing residents to during an emergency is
24	equivalent to taking away an individual without a disability's ability to use their legs and will in
25	fact make it more difficult to successfully evacuate them to a safe location, in my opinion. Also,
26	residents with mobility disabilities who would need to be carried may risk suffering pain,
27	discomfort, and/or embarrassment in the process of being transferred from their mobility devices
28	onto a shuttle seat during loading. Once arriving at the relocation area, residents who are without
	10 C N 417 020/2 HCC (LD)

1	their mobility devices are totally trapped and at a considerable disadvantage compared to other
2	residents and will require considerably more assistance from skeleton staff, who will be
3	preoccupied with other emergency tasks. Therefore, residents must be able to evacuate with their
4	mobility devices (including but not limited to scooters) to ensure that they are able to access the
5	programs and services at the shelter location on a full and equal basis as other residents.
6	29. Brookdale's agreement for procurement of accessible transportation services for
7	residents at Brookdale facilities during emergencies is not sufficient to ensure that vehicles will
8	have enough space to accommodate residents with their mobility devices. The most recent contract
9	disclosed to Plaintiffs was with
10	BKD1599043 and BKD1932355. Relevant language in the contract states that
11	
12	BKD1599044. Such language fails to ensure that accessible transportation will actually be
13	provided to the residents for whom it is needed.
14	the number of residents who use mobility devices such as wheelchairs and scooters at Brookdale's
15	facilities, especially where the capacity of the Brookdale facility and the population thereof is
16	over 100 residents. No evidence has been provided showing that Brookdale updates
17	on the number of residents at each facility who require mobility assistance and/or use mobility
18	devices. Furthermore
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21	Instead,
22	Brookdale's contract with can only be described as a "plan to make a plan," without
23	the detail required to provide people with mobility disabilities and/or vision disabilities full and
24	equal access to Brookdale's transportation services under the ADA.
25	Arrival At Assembly Points and Relocation Sites
26	30. Brookdale's emergency plans and procedures
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5	is a major defect in Brookdale's policies and
6	plans in this area because such accessibility is necessary to ensure that residents with disabilities
7	have full and equal access to Brookdale's services and programs regarding emergency evacuation.
8	31. As discussed above, Brookdale's policy
9	denies residents the opportunity to
10	access the programs and services offered at relocation sites on a full and equal basis with other
11	residents.
12	
13	
14	32. Another major flaw in the plan includes Brookdale's failure to allow residents the
15	chance to participate in emergency planning and in drills. Residents who have mobility disabilities
16	and/or vision disabilities should be involved in emergency planning. Offering residents the
17	opportunity to participate in planning and drills can provide practical experience in the procedures
18	such as evacuation and the options for where and how evacuations may occur. Without this
19	opportunity to gain knowledge and experience, residents with mobility and/or vision disabilities
20	will be at a considerable disadvantage to residents without disabilities during an emergency. In
21	order for such residents to access Brookdale's emergency planning and evacuation services on a
22	full and equal basis as residents without disabilities, Brookdale must provide its residents an
23	opportunity to participate in emergency planning and drills.
24	33. In sum, it is my opinion that as a result of the significant gaps and deficiencies in
25	Brookdale's emergency evacuation plans and procedures described above, residents are denied full
26	and equal access to Brookdale's emergency evacuation programs and services and are placed at a
27	significant risk of injury or loss of life.

34. The analysis and conclusions contained in this Declaration reflect my preliminary findings and conclusions, and these are subject to revision and supplementation, as further information becomes available through the discovery process in this case. My work is continuing. I may supplement, revise or change the opinions contained within this Declaration as I review additional documents produced and additional deposition testimony in this litigation.

I declare under penalty of perjury under the laws of the United States of America that the foregoing is true and correct, and that this declaration is executed at Los Angeles, California this 15th day of August, 2021.

June Isaacson Kailes

Exhibit A



909.208.0122 || jik@pacbell.net || http://www.jik.com

Last update 04.21.21

CV Index

Emergency Publications
Emergency Presentations
Emergency Professional Activities
Health Publications
Health Presentations
Health Professional Activities
Advocacy Publications
Advocacy Publications
Americans with Disabilities Publications
Americans with Disabilities Act Presentations
Americans with Disabilities Professional Activities
Independent Living Publications
Independent Living Professional Activities

Independent Living Professional Activities

Disability Competencies Publications

Disability Competencies Presentations

Technology and Telecommunications Presentations

Technology and Telecommunications Professional Activities

EDUCATION

University of Southern California, Los Angeles, M.S.W. Hofstra University, Hempstead, Long Island, New York, B.A. in Psychology

EMPLOYMENT

Disability Policy Consulting – Los Angeles, CA, January 1985 to Present

Consult for and trains businesses, universities, state associations, government entities, and other not-for-profit organizations. Areas of consulting, writing and training include:

- Building critical actionable disability practice competencies in the worlds of health care and emergency management to insure people with disabilities and others with access and functional needs are integrated and included in service delivery processes, procedures, protocols, policies and training
- Complying with the Americans with Disabilities Act
- Developing and analyzing public policy
- Planning barrier free meetings
- Targeting disability customers: marketing, customer service and product design
- Incorporating universal design principles into existing and new policies, environments and products
- Health, wellness and aging with disability

Associate Director, Harris Family Center for Disability Issues and the Health Policy, Western University of Health Sciences – Pomona, CA, November 2002 to March 2018

- Manages emergency services projects
- Oversees web site development and updates
- Responsible for health care consulting projects
- Trains people with disabilities on strengthening health care advocacy skills
- Develops new and continuing grants and cultivates contracts with public and private funding sources
- Supervises Administrative Assistants, student interns and policy fellows
- Teaches "Disability Competency in the Health Care" an introduction course to disability issues for health professionals

United States Architectural and Transportation Barriers Compliance Board (Access Board) – Washington, D.C.

- Presidential Appointment, Member (1995 2003)
- Chair of Board (March 1999 March 2000)
- Vice Chair of Board (March 1998 March 1999 and March 2000 to March 2001)
- Chair of Technical Programs (March 2002 to present and member 1995 to 2003)
- Chair of Multiple Chemical Sensitivities Committee (1999 to 2003)
- Chair of Ad Hoc Committee on Telecommunication (March 1996 March 1999)
- Member Ad Hoc Committee on:
 - o Passenger Vessels
 - o Public Rights-of-Way

- o Review of ADAAG
- Recreation
- Board Liaison:
 - Passenger Vessel Access Advisory Committee (September 1998 -December 2000)
 - Telecommunication Access Advisory, Committee (June 1996 March 1997)
 - Play Facilities Regulatory Negotiations Committee (March 1996 -August 1996)
 - Air Carriers Access Act Dialogue Group with Department of Transportation (2010 - 2011)

Executive Director, Westside Center for Independent Living, Inc., – Los Angeles, CA (January 1981 - July 1989)

- Center honored as one of "The Top Five" centers in the country
- Instituted a strategic advocacy planning and action and review team
- Expanded services to include: independent living skills training, "linkages" project to prevent institutionalization; several volunteer programs; a South Bay office; and a computer training program
- Diversified public and private funding sources, and established an endowment and a three-month reserve

Services Director, Westside Center for Independent Living, Inc., – Los Angeles, CA (October 1978 - December 1980)

- Developed and expanded peer support, career, and information and referral programs
- Established a local coalition of organizations for improving service coordination to people with disabilities
- Organized and taught courses to recruit and retain peer counselors peer counselors

Psychiatric Social Worker II, Olive View Medical Center – Los Angeles County, CA (February 1977 - September 1978)

- Provided individual, family and group psychotherapy
- Initiated one of the first programs to serve women with disabilities at Planned Parenthood
- Trained staff regarding disability-related psycho-social issues

Medical Social Worker, Rancho Los Amigos National Rehabilitation Center – Downey, CA (July 1973 - February 1977)

• Established first ongoing in service programs for allied health professionals on sexuality and disability

Trained USC medical students and graduate social work students in psychosocial aspects of disability

EMERGENCY PUBLICATIONS

- Kailes, J.I. (Edition 2, 2020) <u>Guidance for Integrating People with Disabilities in Emergency Drills and Exercises</u>,
- Kailes, J.I. (2019) <u>Emergency Power Planning for People Who Use Electricity</u> and Battery Dependent Assistive Technology and Medical Devices
- Roth, M, Kailes, J.I. & Marshall, M, (2018) Getting It Wrong: An Indictment with a Blueprint for Getting It Right Disability Rights, Obligations and Responsibilities Before, During and After Disasters
- Kailes, J.I. (2017) Defining Functional Needs Updating CMIST (2017)
- Kailes, J.I. (2017) Emergency Travel Safety Tips for Overnight Stays, Edition 1
- Kailes, J.I. (2017) Inclusive Event Procedures for Emergencies, Edition I,
- Kailes, J.I. (2017) <u>The National Shelter System and Physical Accessibility Time</u> to Look Under the Hood
- Kailes, J.I. (2017) Training: Maximizing Your ROI!
- Kailes, J.I. (2016) Inclusive Event Procedures for Emergencies, Edition I, in Mid-Atlantic ADA Center and TransCen Inc., <u>Accessible Meetings</u>, <u>Events</u>, and Conferences Guide.
- Kailes, J. I. (Edition 1.0, 2016) <u>Be Real, Specific, and Current: Emergency Preparedness Information for People with Disabilities and Others with Access and Functional Needs,</u>
- Kailes, J.I. (Edition 2.0, 2016) Emergency Preparedness for Personal Assistant Services (PAS) Users, http://www.jik.com/pubs/PAS-EP.pdf
- Kailes, J.I. (Edition 2.0, 2016) Emergency Supplies Kits for People with Disabilities and Activity Limitations, http://www.jik.com/pubs/SupplyChecklist.pdf
- Kailes, J.I. (Edition 1.0, 2015) Guidance for Integrating People with Disabilities in Emergency Drills, Table Tops and Exercises, http://www.jik.com/pubs/ExerciseGuidance.pdf
- Kailes, J. (2015) Tips for Emergency Use of Mobile Devices Edition 2, http://www.jik.com/disaster-individ.html#Guides, also in December, 2015 Use of Mobile Devices "e-ACCESS" newsletter at www.nfpa.org/eaccess pp. 10-24
- Accessible Meetings, Events, and Conferences July 2015, Digital updated version
 of June Isaacson Kailes and Darrel Jones' 1993 work, A Guide to Planning
 Accessible Meetings. The Mid-Atlantic ADA Center and TransCen Inc at
 http://www.adahospitality.org/accessible-meetings-events-conferences-guide/book
- Kailes, J.I. (2015). If You People Would Just Prepare! (pp. 97-110) In Kelman, I. and Stough, I.M. Editors. Disability and Disaster, Explorations and Exchanges Palgrave Macmillan
- Blackstone, S.W. & Kailes, J.I. (2015). Integrating Disaster Resilience Into Your Everyday Practice. (pp. 103-138) In Blackstone, S.W., Beukelman, D.R. &

- Yorkston, K. M. Patient-Provider Communication: Roles for Speech-Language Pathologists and Other Health Care Professionals. Plural Publishing Inc. San Diego, California
- Kailes, J. (2015) Tips for Emergency Use of Mobile Devices Edition 2, http://www.jik.com/disaster-individ.html#Guides
- Emergency Registries... Just Because You Know Where I live Doesn't Mean You Know Where I Am! (2014) (Interview with June Isaacson Kailes, Disability Policy Consultant), NFPA e-Access, (National Fire Protection Association) Part 1 June, 2014, Volume 7, Issue 1, Part II September, 2014, Volume 7, Issue 2
- Kailes, J. and Enders, A. (2014) Access and Functional Needs Emergency Registries: Research Needed, http://www.jik.com/d-rgt.html, jik@pacbell.net
- Kailes, J. and Enders, A. (2014) <u>Access and Functional Needs Emergency Registry Assessment Tool</u>, http://www.jik.com/d-rgt.html, jik@pacbell.net
- Kailes, J. and Enders, A. (2014) <u>Symbolic Planning and Access and Functional Needs Emergency Registries</u>, http://www.jik.com/d-rgt.html, jik@pacbell.net
- Kailes, J. and Enders, A. (2014) <u>Stakeholder Opinions of Access and Functional Needs Emergency Registries</u>, http://www.jik.com/d-rgt.html, jik@pacbell.net
- Kailes, J. and Enders, A. (2014) What is a Registry? http://www.jik.com/d-rgt.html, jik@pacbell.net
- Kailes, J. and Enders, A. (2014) Emergency Registries: Research, http://www.jik.com/d-rgt.html, jik@pacbell.net
- Kailes, J. (2013). <u>Emergency power planning for people who use electricity and battery dependent assistive technology and medical devices Checklist and Podcast.</u> Pacific ADA Center.
- Gershon, R.R.M., Kraus, L.E., Raveis, V.H., Sherman, M.F., and Kailes, J.I. (2013) Emergency Preparedness in a Sample of Persons with Disabilities American Journal of Disaster Medicine, (2013, Winter). 8(1), pp.35-47.
- Illinois-Indiana-Wisconsin Combined Statistical Area Community Preparedness Campaign. (2012). Gear up. Get Ready. It can happen! The Access and Functional Needs (AFN) Emergency Preparedness Resource Guide, (contributed access and functional needs content under contract with Nusura)
- Illinois-Indiana-Wisconsin Combined Statistical Area Community Preparedness Campaign. (2012). Research Report and Options for Consideration in Community Preparedness Campaign Development, Illinois-Indiana-Wisconsin Combined Statistical Area Community Preparedness Campaign, A Collaboration of the Citizen Preparedness Subcommittee of the Regional Catastrophic Planning Team, Research Report and Options for Consideration in Community Preparedness Campaign Development, (contributed access and functional needs content under contract with Nusura)
- Kailes, J.I. (2012) Effectively Including People with Disabilities in Policy and Advisory Groups, Edition 2, 2012, published and distributed by the *Harris Family Center for Disability and Health Policy*, http://www.hfcdhp.org
- Kailes, J.I. (2011). <u>Checklist for Integrating People with Disabilities and Others with Access and Functional Needs into Emergency Planning, Response & Recovery, Kailes-Publications, www.jik.disaster.html, jik@pacbell.net</u>

- Kailes, J. (2011) <u>Emergency Health Information: Savvy Health Care Consumer Series</u>, Published and distributed by Harris Family Center for Disability and Health Policy at Western University of Health Sciences, Pomona, CA
- Stough, L. M., & Kailes, J. I. (2010). "Disabilities and disaster." In K. B. Penuel, M. Statler, J. G. Golson (eds). *Encyclopedia of Disaster Relief* (pp. 109-110). Thousand Oaks, CA: SAGE
- Kailes, J.I. (2010) Be Ready To Go: Disability-Specific Supplies For Emergency Kits. Produced by Nusura, Inc. as part of the Cal EMA Evacuation/Transportation of People with Access and Functional Needs Planning Project
- Kailes, J.I. (2010) Be Ready to Go: Evacuation Transportation Planning Tips for People with Access and Functional Needs. Produced by Nusura, Inc. as part of the Cal EMA Evacuation/Transportation of People with Access and Functional Needs Planning Project
- Kailes, J. I., and George, S. (2010) Disaster Planning For Technology-Dependent Patients Preparation must be ongoing, Advance for Reparatory Care and & Sleep Medicine, Posted on: March 8, 2010
- Kailes, J. I. (2009) Standard, Accessible, and Medical Cots, Kailes-Publications, www.jik.disaster.html
- Kailes, J. I. (2009) Functional Needs Focused Care and Shelter Checklist, Kailes-Publications, www.jik.disaster.html
- Kailes, J. I. (2009) Emergency Power Planning for People Who Use Electricity and Battery Dependent Assistive Technology and Medical Devices, Kailes-Publications, www.jik.disaster.html
- Campbell, V., Gilyard, J., Sinclair, L., Sternberg, T. and Kailes, J. I. (2009) Preparing for and Responding to Pandemic Influenza: Implications for People With Disabilities, American Journal of Public Health | Supplement 2, 2009, Vol 99, No. S2 pp S294–S300
- Kailes, J. I. (2008) Southern California Wildfires After Action Report. Prepared in partnership with the California Foundation for Independent Living Centers and Center Disability Issues and the Health Professions at Western University of Health Sciences, Pomona, CA
- Kailes, J. I. and Enders, A. (2007) Moving Beyond "Special Needs" A function-based framework for emergency management and planning, Journal of Disability Policy Studies, 2007. 17: p. 230-237
- Kailes, J. I. (2007) Serving and Protecting: The Role of Disability and Aging Organizations in Disaster Planning. Institute on Community Integration and the Research and Training Center on Community Living, College of Education and Human Development, University of Minnesota, Vol 20, No. 1
- Kailes, J. I. (2007) Emergency Preparedness Plan Reviews of Developmental and Regional Centers. Prepared under contract with WestEd for the California Department of Development Services
- Kailes, J. I. (2006) Serving and Protecting All by Applying Lessons Learned Including People with Disabilities and Seniors in Disaster Services. Published and distributed by Center for Disability Issues and the Health Professions at Western University of Health Sciences, Pomona, CA and California Foundation for Independent Living Centers

- Kailes, J. I. (2006) Emergency Preparedness: Taking Responsibility For Your Safety - Tips for People with Activity Limitations and Disabilities. (written for the Los Angeles, County, Office of Emergency Management, Emergency Survival Program)
- National Council on Disability. (2005) Saving Lives: Including People with Disabilities in Emergency Planning (researched and drafted under contract for National Council on Disability)
- Kailes, J. I. (2005) Why and How to Include People with Disabilities in Your Emergency Planning Process, Kailes-Publications, www.jik.disaster.html
- Kailes, J. I. (2006) Serving and Protecting All by Applying Lessons Learned Including People with Disabilities and Seniors in Disaster Services, Center for
 Disability Issues and the Health Professions at Western University of Health
 Sciences, Pomona, CA and California Foundation for Independent Living
 Centers, jik@pacbell.net
- Kailes, J. I. (2005) Disaster Services and "Special Needs:" Term of Art or Meaningless Term? International Association of Emergency Managers Bulletin, Special Focus Issue: Emergency Preparedness for Individuals With Disabilities, Part 2, April, 2005
- National Organization on Disability (2005) Report on Special Needs Assessment for Katrina Evacuees (SNAKE) Project (led Analytical / Writing team)
- Kailes, J. I. (2004) Emergency Health Information: Savvy Health Care Consumer Series, 2004. Published and distributed by Center for Disability Issues and the Health Profession, Western University of Health Sciences
- Kailes, J. I. (2002) Evacuation Preparedness: Taking Responsibility For Your Safety: A Guide For People With Disabilities and Other Activity Limitations. Published and distributed by The Center for Disability Issues and the Health Profession, Western University of Health Sciences, Pomona, CA
- Kailes, J. I. (2000) Creating A Disaster-Resistant Infrastructure for People at Risk Including People with Disabilities. Trauma Treatment Professionals' Training. A. Tufan, Duyan, Hacettepe University, School of Social Work, Series No: 005, Universitesi, Sosyal Hizmetler Yuksekokulu, Faith Caddesi No: 195 Ciftasfalt, 06290 Kecioren Ankara, Turkey, 2001
- Kailes, J. I. (1996) 12 Earthquake Tips Sheets for People with Disabilities including People with Visual, Hearing, Mobility, Cognitive, Psychiatric, Multiple Chemical Sensitivities, and Communication and Speech Related Disabilities as well as Tips for Service Animal and Pet Owners, Collecting Emergency Documents, Creating an Emergency Health Information Card, and Tips for People who Use Life Support Systems
- Kailes, J. I. (1996) Living and Lasting on Shaky Ground: an Earthquake Preparedness Guide for People with Disabilities. Published and distributed by California Office of Emergency Services PDF: A, B, C, D, E, F
- Kailes, J.I. (1985) Self-Reliance and Resourcefulness: The Keys to being Quake Safe. Paraplegia News
- Kailes, J. I. (1984, 1985) Quake Safe Part 1 & 2, New World for Persons with Disabilities.

EMERGENCY PRESENTATIONS

- The Term "Access and Functional Needs:" Intent, Origins, What Worked And What Needs Work, Washington State Inclusive Emergency Management Conference, Virtual, 11/18/20
- The Great Shakeout, What Works and What Needs Work? Global Alliance for Disaster Resource Acceleration Disability + Disaster Global Town Hall, World Institute of Disability, Virtual, 10/15/20
- Making Disability Inclusion Real
 - o Delaware Statewide Independent Living Council, 8/31/20
 - o Chinese California Study Group, Los Angeles, CA 10.17.18,
- Integrating Emergency Practice Standards and Expectations into Health Plans' Contracts, with Amber Christ, California Coalition of Long-Term Services and Support Supports, webinar 11/15/19
- The Inconvenient Truth About Registries, Colorado "Getting It Right" Access & Functional Needs Emergency Management Conference, Colorado Division of Homeland Security and Emergency Management, Colorado Springs & Montrose, 11/5,7/19
- National Association of ADA Coordinators
 - o Access to Emergency Services, 4/9/19 Tampa, FL
 - Access to Emergency Services, with John Wodatch, Jim Bostrom, Irene Bowen 10/24-25/18 San Diego, CA
- **Beyond the Rhetoric,** Making it Real, 2/1/19, 12/7/17 KVMR Disability Rap Radio Hour, Nevada County
- Improving Emergency Responses for California Seniors and People with Disabilities (Policy Briefing), Webinar Sponsored by The California Collaborative for Long Term Services and Supports and The California Association of Health Plans with Celine Regalia, Eric Carlson, Wendi West, 10/17/18
- Beyond the Rhetoric Making it Real Rapid Emergency Response Planning for Independent Living Centers, San Francisco 10/28/18 California Foundation for Independent Living Centers
- **Beyond the Rhetoric Making it Real,** Monterey County, CA Operational Area Access & Functional Needs Work Group 10/4/18
- Functional Assessment Service Team,
 - Pacific ADA Center Americans with Disabilities Act Update Conference 2018 9/28/18
 - ADA National Network Learning Session Webinar, with Tarah Heller,
 Nicole Johnson, and Jan Devore, 12/12/17
- Integrating Disability Needs into Emergency Planning, a Summit for Emergency Managers and Partners, Keynote, Beyond the Rhetoric - Making it Real, Keynote, Integrating Disability Needs into Emergency Planning, a Summit for Emergency

- Managers and Partners, Pennsylvania Department of Human Services, Harrisburg, PA 6/13/18
- The Inconvenient Truth About Registries, Power, Alerts and Evacuation. Getting it Right 2018 National Inclusive Disaster Strategies Conference, Washington DC with Maria Town, Director, Houston Mayor's Office for People with Disabilities and Sarah Tuneberg, Geospiza, Inc. 5/24/18
- Getting It Wrong: An Indictment with a Blueprint for Getting It Right Disability Rights, Obligations and Responsibilities Before, During and After Disasters, Getting it Right 2018 National Inclusive Disaster Strategies Conference, Washington DC, with Marcie Roth and Melissa Marshall, 5/23/18
- Enlarging the First Responder Play Bench, SEIU Roundtable Denver International Airport 10/18/17
- ADA National Network Learning Session Webinar 10/12/17: How Functional Assessment Service Teams (FAST) with Tarah Heller, Nicole Johnson, and Jan Devore
- Pacific ADA Center, Americans with Disabilities Act, Update Conference -Access to Health Care Services and Programs under the ADA, Los Angeles, 09.19.17
- Training: Maximizing the ROI! Getting It Right-California, Irvine 6/6 & Sacramento, California 6/8/17, Partnership in Disaster Strategies, Portlight Strategies, Cal OES, Pacific ADA Center, California Foundation of Independent Living Centers
- National Academies Resilient America The State of Resilience Leadership Forum and Community Workshop Engaging with Diverse Populations, with Lori Peek, Nick Kushner & Robin Phofman, Washington, DC, 6/29/16
- Access and Functional Needs Lessons to Apply, Avalon, Long Beach & Signal Hill, California 6/22/16Mass Care: Building Disability Actionable Practice Competencies, North Carolina Emergency Management Fall Conference, Sunset Beach, NC, 0.13.15
- Inclusive Emergency Planning: Lessons to Apply Part 1 of 2
 - North Carolina Emergency Management Fall Conference, Sunset Beach, NC 10.12.15
 - Getting It Right Workshop, Portlight Strategies, Inc., Hampton Roads, Virginia, 2/24-25/15
- Doing Better Together: Modernizing Stakeholder Involvement!
 - o City of Phoenix, 5/24/16 & 8/11/16
 - Inclusive Emergency Preparedness Conference, Cabarrus Health Org, North Carolina, 04.20.16
 - o Getting It Right Workshop, Portlight Strategies Arlington, VA. 7/31/15
 - 2015 EMERGENCY PLANNING CONFERENCE FOR PEOPLE WITH ALL ABILITES, Washington State Independent Living Council (WASILC) in partnership with the Centers for Independent Living of Washington, 6.29.15
- Inclusive Emergency Planning: Lessons to Apply Part 1 of 2, Getting It Right Workshop Hampton Roads, VA, Portlight Strategies, Inc., 2/24-25/15

- Emergency Preparedness Initiative for Persons with Intellectual and Developmental Disabilities Kickoff Event North Carolina Emergency Management, Raleigh, NC, 2/5/2014
- Integrating Access and Functional Needs into Emergency Planning, Response and Recovery – L197 focuses on developing plans that integrate people with disabilities and others with access and functional needs into response and recovery by specifically addressing communication, sheltering, evacuation and transportation concerns. This is the FEMA update to the old G 197 course "Emergency Planning for Functional Needs Populations" which is no longer available
 - o Franklin County, PA, 6/2-3/14
 - o Los Angeles County, CA, 12/15-15/11, 5/14-15/14
 - o Monterey, CA, 8/19-20/14
 - o Oakland, CA, 11/16-17/11
 - o Orange County, CA, 2/25-26/12, 3/25-26/14
 - o Oroville, CA, 10/14-15/14
 - o San Diego, CA, 9/7-8/12, 2/17-18/15
 - o San Bernardino, CA, 8/21-22, 28-29/12, 4/22-23/14
 - o Santa Barbara, CA, 5/6-7/14
 - o Santa Clara, CA, 8/21-22/14
 - o Sonoma, CA, 2/10-11/15
 - o Sonora, CA, 10/27-28/14
- Emergency Preparedness for PAS Users, Webinar 8/23/13, Transcript
- Using FEMA's Functional Needs Guidance in Shelters with Janice Springer, Webinar 6/26/13
- Functional Assessment Service Team Workshops, with California's: Emergency Management Agency, Department of Social Services and the American Red Cross
 - o Overviews
 - FEMA's 2012 NATIONAL PREPAREDNESS SYMPOSIUM "Increasing Preparedness to Build Community Resilience" in Crystal City, VA, 8/7-8/12
 - Arizona, 6/29/12
 - Promising Disability Inclusive Practices From FEMA's ODIC http://gettingreal-ii.webcaston.tv/ Getting Real II Conference 9/12-14/11 with Richard Devylder and Michael Logan
 - State Team Trainings
 - Hawaii, 6/19-20/12
 - Minnesota, 10/25-25/11
 - Missouri Team Trainings, 7/6-7/11
 - State of California Team Trainings:
 - Oakland, 5/13-14/09
 - Los Angeles, 5/20-21/09
 - Sacramento, 6/25-26/09, 6/22-23/11
 - o County Team Trainings:

- Contra Costa, 3/13-14/12
- Los Angeles / Orange, 4/7-8/10, 4/6-7/11, 4/12-13/12
- Kern, 5/12-13/10
- Monterey, 5/24-25/10
- Santa Clara / Monterey, 2/910/11
- San Diego, 6/26-27/12
- San Francisco / San Mateo, 2/23-24/11, 3/27-28/12
- Riverside / San Bernardino, 4/19-20/11, 4/23-24/12
- Placer, 6/22-23/11
- o Cities
 - Richmond, California, 6/1-2/11
- Whole Community Planning
 - Plenary Beyond Special: Real Whole Community Planning, 2012 FEMA's NATIONAL PREPAREDNESS SYMPOSIUM "Increasing Preparedness to Build Community Resilience" in Crystal City, VA, 8/7/12
- Emergency Registries for People with Disabilities:
 - A Realistic Look at Emergency Registries for People with Disabilities - An Effective Tool or False Expectations? Where Are We? Partners in Emergency Preparedness Conference, Tacoma, WA, 4/2/08
 - Emergency Registries for Evacuating and/or Assisting People with Disabilities & Activity Limitations - An Effective Tool or False Expectations, Association of University Centers on Disabilities (AUCD) Webcast 8/31/09
 - Emergency Registries and Alternatives: Tools for Decision Makers, Getting Real II- Inclusive Emergency Management for the Whole Community, Arlington, VA 9/12-14/11
 - Emergency Registries: An Objective Analysis Tool, National Association of County and City Health Officials (NACCHO) Webinar, 9/1/11
 - Emergency Registries for People with Disabilities Questions & Cautions, National Council on Independent Living Annual Conference 7/15/11
 - Emergency Registries and Technology Alternatives, California State Northridge Technology Conference, With Richard Devylder, Chief, Office for Access and Functional Needs, San Diego, CA, 3/20/14
- Evacuation Planning for People with Access and Functional Needs:
 - California Gold Country Tuolumne and Amador Counties with Gary Gleason, Nusura, 9/21-22/11
 - o Access Service, Los Angeles with Gary Gleason, 2/28/11.
- Tabletop Exercise for People with Access & Functional Needs with Kathleen Henderson, Office of Emergency Services, Riverside Department of Public Health, 10/25/10

- Emergency Tech Prep: Power Options for Devices During Long Power Outages - National Leadership Summit on Emergency Management and Assistive Technology Reutilization - Successful Strategies, Innovative Partnerships, Futures Planning, Washington, D.C., 2/24/10
- Moving Beyond Special Needs—Making Disaster Lessons Real and Operationalizing Functional Needs! Association of University Centers on Disabilities (AUCD) Webcast 8/31/09
- Disability Disaster Specific Issues: Are You Really Ready? Plan Now or Suffer & Muddle Through Later! Your Role in Disaster Planning, Preparedness, Response, & Recovery, County of Riverside Public Health 2009: 2/17, 4/6-7
- Disaster Lights & Disaster Heavies: Relevant Emergency Preparedness Information for People with Disabilities, County of Riverside Public Health 2009 2/17/09
- Functional Needs (formerly special needs) Planning for Disasters, 1/16/09.
- 10th Annual Community Services Bureau Conference Sponsored by: Montana Department of Public Health & Human Services; Senior, Long Term Care Division's Community Services Bureau; & Montana Case Management Association, Billings, MT, 10/2/08
- Together We Do Better, Meeting Accessibility and Functional Needs in a Disaster, Fourth Annual Disaster Preparedness Conference For Santa Clara County Community-Based Organizations, Faith-based Organizations, and Government Partners, 3/24/09
- Lesson for Montana—From the California Wildfires? 10th Annual Community Services Bureau Conference, Montana Department of Public Health & Human Services; Senior, Long Term Care Division's Community Services Bureau; & Montana Case Management Association, Billings, MT, 10/3/08
- Engaging People with Disabilities in Disaster Preparedness, Response, & Recovery, Ignite and Unite: A Partnership Summit To Strengthen Communities (Hosted by White House Office of Faith-Based & Community Initiatives & California Volunteers) Sacramento, CA, 8/18/08
- Working Emergency Planning & Preparedness Forum: Including People With Disabilities & Activity Limitations
 - Sponsored by City of San Diego Disability Services Program, Area Board XIII on Developmental Disabilities and Access to Independence, 1/23/08
 - 2008 Stakeholder Planning Conference, Kern County Office of Emergency Services, Bakersfield, CA, 2/20/08
- California Foundation for Independent Living Centers Access to Readiness Summit "Increasing Disability Preparedness Together" Functional Assessment Service Teams (FAST) - Southern California Wildfires Response with Vicki Cuscino, Richard Devylder, Helen Lopez, Andy Mudryk, Shannon McCrosky, Christie Rudder, Martin Sweeny, Sacramento, CA, 1/11/08

- Disaster Lights & Disaster Heavies: Relevant Emergency Preparedness Information for People with Disabilities
 - o County of Riverside Public Health Department. 2/17/09, 4/6-7/09
 - Making Emergency Preparedness Real for People with Disabilities, Emergency Preparedness and Disaster Planning for Children with Special Health Care Needs, Los Angeles, CA, 4/214/08
 - 10th Annual Community Services Bureau Conference, Sponsored by: Montana Department of Public Health & Human Services; Senior, Long Term Care Division's Community Services Bureau; & Montana Case Management Association, Billings, MT, 10/3/08
 - o ILRU Webcast: Part 1-11/9 & Part 2 11/16/07
- Are You Really Ready? Plan Now or Suffer & Muddle Through Later! Your Role in Disaster Planning, Preparedness, Response, & Recovery
 - County of Riverside Public Health Department, 3/17/08, 2/17/09, 4/6-7/09
 - o An Educational Summit for Utah's Long-Term Care Providers, South Towne Exposition Center, Salt Lake City, UT, 7/17-18/08.
 - o City of Oakland, CA, 10/1/07
 - Faith Communities and Emergency Preparedness An All Persons Approach Conference, Minnesota, MN, 8/16/07
 - Really Ready: Disaster Preparedness for Long Term Care,
 California Association of Health Facilities, Garden Grove, CA,
 9/5/07
- Infusing Disability Literacy & Competency in Emergency Planning, 2007
 Great Lakes Homeland Security Training Conference & Expo, Grand
 Rapids, MI, 5/9/07
- Applying Disaster Lessons Documented & Moving Beyond Special Needs
 - Lesson for Montana From California Wildfires? 10th Annual Community Services Bureau Conference, Sponsored by: Montana Department of Public Health & Human Services; Senior, Long Term Care Division's Community Services Bureau; & Montana Case Management Association, Billings, MT, 10/3/08
 - Functional Needs versus Special Needs Planning and Response -Moving Beyond Special Needs — Making Disaster Lessons Real! Partners in Emergency Preparedness Conference, Tacoma, WA, 4/2/08
 - Minnesota Department for Health Office of Emergency Preparedness, Are You Really Ready? Plan Now or Suffer & Muddle Through Later! Your Role in Disaster Planning, Preparedness, Response, & Recovery Faith Communities & Emergency Preparedness – An All Persons Approach Conference, St. Paul, MN, 8/16/07
 - 2007 Great Lakes Homeland Security Training Conference & Expo Grand Rapids, MI, 5/10/07

- National Community Emergency Response Team (CERT)
 Conference, Los Angeles, CA, 5/16/06
- o Southwest Conference on Disability, Albuquerque, NM, 10/4-6/06
- Making Lessons Documented Real!
 - Analysis of Disaster Plans of 21 Regional Centers and 7
 Developmental Centers Department of Developmental Services
 Emergency Preparedness Advisory Committee, Sacramento, CA, 10/18/06
 - o World Bank, Washington, D.C., 1/23/07
 - Access to Readiness Disability Summit on Emergency Preparedness, Sacramento, CA, 12/11/06
 - Department of Developmental Services, Emergency Preparedness Advisory Committee, Sacramento, CA, 10/18/06
 - O Integrating Disability Issues into Instructors' Toolkits, with Hilary Styron and Elizabeth Davis. National Center for Biomedical Research and Training 4th Annual Instructor Professional Development Conference Louisiana State University, Baton Rouge River Center Baton Rouge, LA, 8/17/06
 - Working Conference on Emergency Management and Individuals with Disabilities and the Elderly, HHS Conference at Marriott Wardman Hotel, Washington, D.C., 6/30/06
- Policy Issues Emergency Preparedness for People with Disabilities
 - California Foundation of Independent Living Centers, Sacramento, CA, 2/27/06
 - Lanterman Regional Center, Los Angeles, CA, 1/30/06, 1/14-18/05, 12/8/00
- Plan Now or Suffer & Muddle Through Later! The Role of Disability Community Based Organizations in Disaster Planning, Preparedness, Response, Recovery & Mitigation Activities
 - Emergency Preparedness Plan Reviews of Developmental and Regional Centers, California Department of Developmental Disabilities - Emergency Preparedness Advisory Committee, Sacramento, CA, 8/9/07
 - Residential and Day Program Providers Lanterman Regional Center, Los Angeles, CA 11/14/06 and 1/13/07
 - Online Course, sponsored by IL NET: ILRU/NCIL National Training and Technical Assistance Training Program &Utah State University Center for Persons with Disabilities, 10/2-20/06, 1/22-2/9/07
 - 2005 Virginia Public Safety Outreach Conference, Richmond, VA, 11/15/05
 - Association of Programs Rural Independent Living, Honolulu, HI, 10/8/05
 - o State Independent Living Council, Sacramento, CA, 5/25/05

- The Role of the State Independent Living Council in Disaster Services, with Bill Scott and Glen White, State Independent Living Council Congress, Phoenix, AZ, 1/4-6/05
- Lanterman Regional Center, Los Angeles, CA, 1/30/06, 1/14-18/05, 12/8/00
- Emergency Preparedness for People with Disabilities
 - Texas State Independent Living Council Annual Conference, El Paso, TX, 3/6/06
 - Prepare For All Abilities, 2005 Virginia Public Safety Outreach Conference, Richmond, VA, 11/15/05
 - Lanterman Regional Center, Los Angeles, CA, 10/10/06, 2/15/06, 1/21/05, 7/17/03, 3/23/98
- In the Aftermath of Katrina, with Lex Frieden, Michael Winter, Thomas Kelley, Glen White, John Lancaster, and Gary Maddox, Association of Programs Rural Independent Living, Honolulu, HI, 10/8/05
- Emergency Preparedness for People with Disabilities, sponsored by National Organization on Disability, U.S. Department of Homeland Security & National Capitol Region, 9/22-25/04
 - Developing a Strategic and Inclusive Approach to Emergency Preparedness and Disaster Planning that Benefits People of All Abilities with Vincent Campbell, Ph.D., Center for Disease Control and Prevention (CDC), Marco Pardi - CDC, Office for Terrorism Preparedness and Emergency Response, Dr. Michael Fox - University of Kansas, Dr. Tony Cahill - University of New Mexico
 - Funding Emergency Preparedness for People with Disabilities: A
 Workshop for Grant Makers and Grant Seekers with Jeanne Argoff
 Disability Funders Network (DFN), Susan Dooha, Director—The
 Center for Independence of the Disabled, New York (CIDNY),
 Harilyn Rousso DFN
- Emergency Evacuation for People with Disabilities
 - National Fire Protection Association NFPA World Safety, Conference & Exposition® Salt Lake City, UT, 524/004
 - Select Summit on: Disability & Health A Call to Action, Des Moines, IA, November 2003
 - Mt. San Antonio College, Emergency Medical Technician-Paramedic Training Program, March 2002
- Emergency Preparedness for People with Disabilities, an Interagency Seminar of Exchange for Federal Managers, U.S. Department of Labor, Washington DC., December 2003
 - o Egress 3 Breakout Session with Edwina Julliet
 - Putting it All Together, Closing Plenary Session with Elizabeth Davis and Edwina Julliet
- Disaster Preparedness and Emergency Response: Independent Living Experience and Future Direction at NCIL Annual Conference, Washington, DC, June 2003 with Elizabeth Davis and Jennifer Rowland

- Emergency and Disaster Preparation for People with Disabilities on a Webcasts May 2003, archived at http://www.ilru.org/ku-ilru/online/Webcast.html
- Hurricanes, Floods and Quakes ILCs Responsibilities in Disaster Preparedness and Response at NCIL Conference, Washington, DC. June 1997
- Learning from Living and Lasting on Shaky Ground: Earthquake Preparedness for People with Disabilities
 - o Earthquake Preparedness Workshop. Lanterman Regional Center, Glendale, CA. 1997 2001
 - Technology and People with Disabilities. Los Angeles, CA. March 1996
- Turkey, February 2001
 - o Anadolu University, Special Education Department, faculty, students and parents, Eskisehir
 - o Karamursel School for the Deaf
 - Representatives from Turkish Government, disability advocacy organizations and NGOs, Turkish Red Cross, and hospital and rehabilitation schools for deaf/blind, Ankara
 - Bosphorus University's Istanbul Disaster Preparedness Education Project, Istanbul Community Impact Project, Kandilli Observatory & Earthquake Research Institute, Istanbul
- Kobe, Japan
 - Committee for the Global Assessment of Earthquake Countermeasures Five-year Assessment Project Team, Disaster Management Division, Office of the Governor, Hyogo Prefectural Government, August - September 1999, January 2001
 - International Seminar of Reconstruction and a New Barrier Free Environment: Toward a Society for All. October 1995
- People with Disabilities and Disasters: A Civil Emergency Management Course at California Specialized Training Institute (CSTI), Los Angeles, CA. February 1983 & San Francisco, CA. March 1984
- Attitudes Towards People With Disabilities at California State University, Long Beach, CA. November 1983
- Emergency Management for People with Disabilities at City of Santa Monica, CA. June 1983

EMERGENCY PROFESSIONAL ACTIVITIES

State:

 California Emergency Management Agency, California Standardized Emergency Management Systems (SEMS) Mass Care and Shelter Committee member (2007 to present)

- California Emergency Management Agency, California Standardized Emergency Management Systems (SEMS) Technical Group member (2007 to 2015)
- California Emergency Management Agency, California Standardized Emergency Management Systems (SEMS) Training and Exercise Committee member (2007 to 2015)
- California State Emergency Plan Revision, participant (2008 to 2010)
- California State Citizen Corps Council, member (2008 to 2013)
- Nobody Left Behind: Disaster Preparedness for Persons with Mobility Impairments, University of Kansas Consulting with and Advisory Group (2003 – 2004)
- California's Office of Emergency Safety, member of Planning Group for People with Disabilities (1986)

National:

- FEMA National Advisory Council, member 2010 8/2019
 - o The National Advisory Council (NAC) was established by the enactment of the Post-Katrina Emergency Management Reform Act of 2006 to ensure effective and ongoing coordination of Federal preparedness, protection, response, recovery, and mitigation for natural disasters, acts of terrorism, and other human caused disasters. The NAC advises the FEMA Administrator on all aspects of emergency management. The NAC incorporates state, tribal and local governments, and private sector input in the development and revision of the national preparedness goal, the national preparedness system, the National Incident Management System, the National Response Framework, and other related plans and strategies.
- American Red Cross Disability Advisory Committee 2016 2017
- American Red Cross Advisory Council Sub-Project: Shelter Facility Survey access and functional needs update (2014-15) a multi-sector effort to update ARC's Shelter Survey Tool to meet ADA Law and contemporary needs 2014 2015
- Consortium for Citizens with Disabilities Emergency Management Task Force
 - \circ Member (2007 2011)
 - o Co-Chair (2011 to 2013)
- National Council on Independent Living Emergency Preparedness Committee
 - o Co-Chair (2011 to 2012)
 - o Member (2011 to present)
- National Fire Protection Association Center for High Risk Outreach Fire Safety for People with Disabilities, Task Force (2004 to 2015)
- Department of Homeland Security
 - Transportation Security Administration, Disability Coalition (2009 to present)
 - o National Response Plan Special Needs Work Group (2006 2007)
 - Function and Medical Support Sheltering (FMSS) Target Capabilities List, Co-Chair (2006-2007)

International:

Development of the Sendai Framework "Words into Action" Implementation Guide for Civil Society, Volunteers, Organized Voluntary Work and Community-based Organizations (2015)

Work Groups:

- International Association of Emergency Managers (IAEM) and National Emergency Management Association (NEMA) Work Group to adapt and adopt for guidance the 2014 Checklist for Integrating People with Disabilities and Others with Access and Functional Needs into Emergency Planning, Response & Recovery, 2014 - 2015
- At-Risk Populations and Pandemic Influenza: Planning Guidance for State, Territorial, Tribal and Local Health Departments, Association of State and Territorial Health Officials, Work Group Member (February 2008 – May 2008)
- National Recreation and Park Association and National Recreation Foundation's Community Preparedness and Response, Work Group Member (September 4-5, 2003, Washington, D.C.)
- Emergency Preparedness Working Meeting, CDC & American Association on Health and Disability (June 15-16, 2004, San Antonio, Texas)
- Nobody Left Behind: Disaster Preparedness for Persons with Mobility Impairments, University of Kansas Consulting with and Advisory Group (2003 – 2004)

HEALTH PUBLICATIONS

- 1. Kailes, J., Delgado, H. (1974). "Sex Counseling for Those with Spinal Cord Injuries." Social Casework 55(10): 622-627
- 2. Bullock, K., Taylor (1981). Guidelines for Discussion of Videotape: Reflections on Adolescence (Instructor's Manual). Los Angeles, Orthopedic Hospital
- 3. Kailes, J. (1981). Sexuality and Disability and the Social, Political & Economic World of Disability, Wright Institute of Los Angeles
- 4. Kailes, J., Katz, A., Martin, K., (1982). Personal and Family Counseling. A Handbook of Services for the Handicapped. Greenwood Press
- 5. Kailes, J. (1989). Aging with a Disability: Another Advocacy Priority. Options 3 (1)
- 6. Kailes, J. (1990). Aging with a Disability: Another Advocacy Priority. Networker, United Cerebral Palsy Association. 3
- 7. Kailes, J. (1991). <u>Aging with a Disability: Another Advocacy Priority</u>. Aging, Disability and the Nation's Productivity, Switzer Monograph, National Rehabilitation Association
- 8. Kailes, J. (1992). <u>Aging with a Disability: Educating Myself</u>. Generations, Journal of the American Society on Aging XVI (1) pp. 75-77

- 9. Kailes, J. (1992). Aging with a Disability: Educating Myself. Aging and Disabilities: Seeking Common Ground, Editors. A. Eustis, Baywood Publishing Company, Inc. Amityville, New York
- 10. Kailes, J. (1995). "Fit to be Tried." Mainstream 19(9): 37-46
- 11. Kailes, J. (1995, 1997, 1998, 2000). Health, Wellness and Aging with Disability, KAILES Publications.
- 12. Kailes, J. (1995). "Midlife Cripdom: Getting Fewer Miles per Gallon?" The Disability Rag 16 (4)
- 13. Kailes, J. (1996, 1997, 1998, 2001, 2002). Be a Savvy Health Care Consumer Your Life May Depend on It!, Edition 5, 1st Edition 1997, KAILES Publications.
- 14. Kailes, J. (1998). Managing Your Own Health Care You've got to be a Savvy Consumer to Make Sure Your Needs are Met. MAINSTREAM. 22: 31-34
- 15. Kailes, J. (1999). Bridging the Great Divide Independent Living and Health Care: Systems Change Strategies and Resources--Learning from the Trenches. ILRU Houston, TX. http://www.ilru.org/ilnet/ilnetbks.html
- 16. Kailes, J. (2000). <u>Can Disability, Chronic Conditions, Health and Wellness Coexist?</u> KAILES Publications, jik@pacbell.net.
- 17. Kailes, J. (1995, 1996, 2000, 2002). Resource List: Wellness, Self-Care, Exercise & Aging with Disability, Edition V,
- 18. Kailes, J. (2001). Aging with Disability Good News and Bad News. Western U-View. XX: 17
- 19. Kailes, J. (2001). Health Care Providers and Health Care Consumers: The Complaint Gap, KAILES Publications, jik@pacbell.net
- 20. Kailes, J. (2001). Health and Wellness for Women with Disabilities. Orchid. Summer Edition, NCODH, CB#8185, UNC-CH, Chapel Hill, NC 27599-8185
- 21. Kailes, J. (2001). Making the Most of Your 15 Minutes. Orchid. Summer Edition, NCODH, CB#8185, UNC-CH, Chapel Hill, NC 27599-8185: 54.
- 22. Kailes, J. (2002). Are you an active partner in your health care? The IEHP Pulse, Member Newsletter, 303 E. Vanderbilt Way, Suite 400, San Bernardino, CA 92408. 13: 8
- 23. Kailes, J., Richards, L., Heinsohn, D., Lin, R., Shepard, R. (1999).
 Teleconference: Bridging the Great Divide Independent Living and Health Care: Individual Services, Advocacy and Resources. Houston, IL Net: NCIL/ILRU, 2323 S. Shepherd, Suite 1000, Houston, TX 77019
- 24. Premo, B., Kailes, J., Schwier, E., Richards, C., (2003). Adults with Disabilities in Medi-Cal: The Beneficiary Perspective, Medi-Cal Policy Institute, 476 Ninth Street, Oakland, CA 94607, Tel: 510.286.8976, Fax: 510.238.1382, http://www.medi-cal.org/topics/view.cfm?itemID=21512
- 25. Kailes, J., Shimomura, S., McGory, R., Premo, B. (2003). Pharmacy Times, Communicating with Your Deaf and Hard-of-Hearing Patients, September 2003, http://www.pharmacytimes.com

- 26. Story, M., Winters, JMW., Premo, B., Kailes, J., Winters, JM. (2003) Understanding Barriers to Healthcare Caused by Inaccessible Medical Instrumentation. In Proceedings of RESNA 2003 International Conference. Arlington, VA: RESNA Press
- 27. Kailes, J. Emergency Health Information: Savvy Health Care Consumer Series, 2004. Published and distributed by Center for Disability Issues and the Health Profession, Western University of Health Sciences, 309 E. Second Street, Pomona, CA 91766-1854, Phone: (909) 469-5380, TTY (909) 469-5520, Fax: (909) 469-5407, www.cdihp.org
- 28. Kailes, J., The Health Care Partnership: Barriers to Care- Part 2: The Consumer's Viewpoint, in: Kemp, B., Mosqueda, L., Ed. (2004). <u>Aging with a Disability: What the Clinician Needs to Know, John Hopkins University Press</u>
- 29. Winters, JMW., Story, M., Barnekow, K., Premo, B., Kailes, J., Schwier, E., Winters, JM. (2004). A Delphi Study to Develop a National Survey of Accessibility of Medical Instrumentation. In Proceedings of RESNA 2004 International Conference. Arlington, VA: RESNA Press
- 30. Winters, JMW, Story, MF, Barnekow, K, Premo, B, Kailes, JI, Schwier, E, Winters, JM (2004). A National Survey of Accessibility of Medical Instrumentation. In Proceedings of RESNA 2004 International Conference. Arlington, VA: RESNA Press
- 31. Kailes, J., Mac Donald, C. *ADA Resources*, 2004. Published and distributed by the Center for Disability Issues and the Health Professions, Western University of Health Sciences, 309 E. Second Street, Pomona, CA 91766-1854
- 32. Kailes, J., Mac Donald, C. *Choosing & Negotiating an Accessible Business Location*, 2004. Published and distributed by the Center for Disability Issues and the Health Profession, Western University of Health Sciences, 309 E. Second Street, Pomona, CA 91766-1854
- 33. Kailes, J., Mac Donald, C. *Health Care Facilities Access*, 2004. Published and distributed by the Center for Disability Issues and the Health Profession, Western University of Health Sciences, 309 E. Second Street, Pomona, CA 91766-1854
- 34. Kailes, J., Mac Donald, C. *Importance of Accessible Examination Equipment*, 2004. Published and distributed by the Center for Disability Issues and the Health Profession, Western University of Health Sciences, 309 E. Second Street, Pomona, CA 91766-1854
- 35. Kailes, J., Mac Donald, C. *Improving Accessibility with Limited Resources* 2004. Published and distributed by the Center for Disability Issues and the Health Profession, Western University of Health Sciences, 309 E. Second Street, Pomona, CA 91766-1854
- 36. Kailes, J., Mac Donald, C. *Tax Incentives for Improving Accessibility*, 2004. Published and distributed by the Center for Disability Issues and the Health Profession, Western University of Health Sciences, 309 E. Second Street, Pomona, CA 91766-1854
- 37. Kailes, J., Mac Donald, C. *Tools for Decreasing Health Care Barriers*, 2004. Published and distributed by the Center for Disability Issues and the Health

- Profession, Western University of Health Sciences, 309 E. Second Street, Pomona, CA 91766-1854
- 38. Schwier, E., Kailes, J., Jansma, M., Premo, B., Mac Donald, C. *The Experiences and Perspectives of Medi-Cal Consumers with Disabilities*, August 2004, Inland Empire Health Plan
- 39. Kailes, J. Shield Your Health: Making Preventive Health Care Work for You A Resource Kit for People with Physical Disabilities, 2005. Published and distributed by the Center for Disability Issues and the Health Professions, Western University of Health Sciences, 309 E. Second Street, **Pomona, CA** 91766-1854
- 40. Center for Disabilities Issues & the Health Professions, Center for Health Care Strategies, and The Lewin Group, (2005) Developing Health Plan Performance Standards for Serving People with Disabilities in Medi-Cal, www.chcf.org
- 41. Kailes, J. (2005). Workshop on Disability in America, an New Look: summary and papers: based on a workshop of the Committee on Disability in America: a New Look, Board on Health Sciences Policy. Field, M., Jette, J.M., and Martin, L. editors, Chapter K A User's Perspective on Midlife (Ages 18-65) Aging with Disability, Institute of Medicine
- 42. Palsbo, S., Kailes, J. (2006). "Disability-Competent Health System." <u>Disability Studies Quarterly</u> 26(2)
- 43. Kailes, J.I. (2006). The Patient's Perspective on Access to Medical Equipment. In J. Winters and M. Story (Ed.), Medical Instrumentation: Accessibility and Usability Considerations (pp. 3-14). Boca Raton, FL: CRC Press
- 44. Winters, JMW., Story, M., Barnekow, K., Kailes, J., Premo, B., Schwier, E. (2006). Results of a National Survey on Accessibility of Medical Instrumentation for Consumers. In J. Winters and M. Story (Ed.), Medical Instrumentation: Accessibility and Usability Considerations (pp. 15-32). Boca Raton, FL: CRC Press
- 45. Kailes, J., Premo, B., & Richards, C. (2006). Toward a New Health Care Policy: Accessible Medical Equipment and Instrumentation. In J. Winters and M. Story (Ed.), Medical Instrumentation: Accessibility and Usability Considerations (pp. 49-70). Boca Raton, FL: CRC Press
- 46. Kailes, J.I., (2006). Making Preventive Health Care Work for You A Resource Guide for People with Physical Disabilities, Published and distributed by the Center for Disability Issues and the Health Professions, Western University of Health Sciences, 309 E. Second Street, Pomona, CA 91766-1854; voice/TTY 1-800-832-0524; e-mail ahcs@westernu.edu, www.CDIHP.org
- 47. Kailes, J., Premo, B., & Richards, C. (2007). Exploring Key Issues on Accessible Medical Equipment and Instrumentation: Summary of Meetings, Published and distributed by Center for Disability Issues and the Health Profession, Western University of Health Sciences, 309 E. Second Street, Pomona, CA 91766-1854, Phone: (909) 469-5380, TTY (909) 469-5520, Fax: (909) 469-5407, Email: ahcs@westernu.edu, www.CDIHP.org
- 48. Kailes, J.I., (2008) <u>5 "G's" Getting Access to Health Care for People with Physical Disabilities</u>, 2008 Version 1, Published and distributed by Center for

- Disability Issues and the Health Professions, Western University of Health Sciences, 309 E. Second Street, Pomona, CA 91766-1854, Email: <u>jik@pacbell.net</u>
- 49. Story, M., Schwier, E., Kailes, J. (2009). <u>Perspectives of patients with disabilities on the accessibility of medical equipment: Examination tables, imaging equipment, medical chairs, and weight scales. Disability and Health Journal (2) 169-179</u>
- 50. Kailes, J.I & Lee, M. (2009) Mammography: Addressing Equipment Design, Published and distributed by Harris Family Center for Disability and Health Policy, Western University of Health Sciences, Pomona, CA www.HFCDHP.org, jik@pacbell.net
- 51. Kailes, J.I & Lee, M. (2009) Importance of Accessible Mammography Equipment, Published and distributed by Harris Family Center for Disability and Health Policy, Western University of Health Sciences, Pomona, CA www.HFCDHP.org, jik@pacbell.net
- 52. Gardner Bonneau Au, D.J. & Kailes, J.I. (2010). Winter, Accessible Health Care: More Than Just Getting Through the Door <u>Ergonomics In Design</u>. Winter 2010, 5-10
- 53. Story, M., Kailes, J., Mac Donald, C. (2010). The ADA in action at health care facilities <u>Disability and Health Journal</u> (3) 245-252
- 54. Kailes, J.I., (2011). Quality Services for People with Disabilities and Activity Limitations, (4 part online training package), Harris Family Center for Disability and Health Policy, Western University of Health Sciences, (909) 469-5385, hfcdhp@westernu.edu, https://www.hfcdhp-training.org/
 - Part 1, defines "disability" and "activity limitations" and looks at how common disability is. It also explores how disability increases with age
 - Part 2 looks briefly at the Americans with Disabilities Act of 1990 and how it impacts health care services
 - Part 3 considers how health care worker's attitudes and beliefs toward people with disabilities and activity limitations may affect the quality of health care
 - Part 4, explores issues involving physical, communication, and medical equipment access—particularly, the "hassle factors" experienced by people with disabilities and activity limitations when trying to obtain health care
- 56. Kailes, J.I. <u>Effectively Including People with Disabilities in Policy and Advisory Groups</u>, Edition 2, 2012, published and distributed by the Harris Family Center for Disability and Health Policy, http://www.hfcdhp.org
- 57. Accessible Meetings, Events, and Conferences, July 2015, Digital updated version of June Isaacson Kailes and Darrel Jones' 1993 work, A Guide to Planning Accessible Meetings. The Mid-Atlantic ADA Center and TransCen Inc at http://www.adahospitality.org/accessible-meetings-events-conferences-guide/book
- 58. Kailes, J.I., <u>Providing Health Care for People with Disabilities: Competency Planning</u> Checklists, Edition 3, 2016.
- 59. <u>Transfer Assistance For People with Mobility and Disability Limitations On And Off an Exam Table</u>, (2017) 4.2 minutes, J.I. Kailes script for <u>Inland Empire Health Plan</u>

- 60. <u>Using Accessible Scales to Weigh People with Mobility and Disability Limitations</u>, (2017) 4 minutes, J.I. Kailes script for <u>Inland Empire Health Plan</u>
- 61. Kailes, J.I. (Edition 2, 2020) <u>Health Plans Strengthening Emergency Roles and Partnerships</u>
- 62. Kailes, J.I. (Edition 2.1 2020) <u>Preparing for Hospitalization During COVID-19</u> Pandemic: A Checklist for People with Disabilities
- 63. Kailes, J.I. (Edition 2, 2020) <u>ADA Compliance with Visitations in Healthcare Facilities: Coronavirus Pandemic Guidance for Advocates</u>
- 64. Kailes, J., Disasters and Disability: Rhetoric and Reality, (pp. 251-268) 2021. In Lollar, D., Horner-Johnson, W., Froehlich-Grobe, K., (Ed.), Public Health Perspectives on Disability: Science, Social Justice, Ethics, and Beyond *(2nd Ed.):* Springer Science+Business Media, LLC, part of Springer Nature

HEALTH PRESENTATIONS

Feedback on Models of Care, Cerebral Palsy Research Network, Investigator Meeting, Virtual, 2/1/21

Equity, Inclusivity, Specificity: Moving the Disability Inclusion Needle, Constant Associates, Los Angeles, California, Virtual, 3/12/21

Disability and Trauma While Hospitalized During the Covid-19 Pandemic, KVMR Radio, Nevada City, California, Disability Rap, 12/11/20

Department of Health Care Services, Physical Accessibility Review, PL 1-006 revised facility site review tool, Kaiser Permanente Southern California, 12/02/19

Be an Active Health Care Consumer Upping Your Game, The Independence Center, Colorado Springs, CO, 7/26/19

The Joys of Health Care Through the Disability Lens - The Hidden Health Care Heavy Hassles - We Wish We Would Didn't See, The Independence Center, Colorado Springs, CO, 7/26/19

Consumer Perspectives, User Acceptance/Adherence, and Abandonment Of Mhealth Technology Solutions, LiveWell RERC State of the Science Conference: The Future of mHealth and mRehab for People with Disabilities, Rehabilitate Week, Toronto, Canada 6/25/19

Making Policies, Educating & Contracting Real - Promising Practices from the Trenches, Health Net, Los Angeles, webinar, 06/20/19

Physical Access Surveys History, Centene, National Council on Independent Living, webinar, 5/23/19

Health Care Facilities, Health Care Equipment, and Making Policies Real - Promising Practices from the Trenches, , with Jim Bostrom, Carol Bradly, and Irene Bowen, National Association of ADA Coordinators Tampa, FL, 04.09.19

Building and Sustaining Effective Emergency Community Response Partnerships: Integrating Health Plans and Disability Service Community Providers and Advocates, APHA's 2018 Annual Meeting, San Diego, CA 11/14/18 with Marcie Roth, Judith Katzburg, Michael McClendon

National Association of ADA Coordinators, San Diego, CA 10/23/18

- Health Care Implementing Policies for Accessibility with Jim Bostrom, Carol Bradley, Kaylan Dunlap
- **Health Care Facilities Building and Site Issues** with Jim Bostrom, Carol Bradley, Kaylan Dunlap
- **Diagnostic Medical Equipment and Accessible Healthcare** with Jim Bostrom, Carol Bradley, Irene Bowen, Kaylan Dunlap

Pacific ADA Center, Americans with Disabilities Act, Update Conference

 Access to Health Care Services and Programs under the ADA, Los Angeles, 09.19.17

Disability Competency Services

- L.A. Care, Los Angeles, California 12/28/17
- Care1st, Monterey Park, California 9/2/16, 9/19/17, 9/24-25/18; San Diego 10/28/16, 11/16/18
- UCLA OB/GYN Clinic, Los Angeles, California 5/26/16
- Regal Medical Group, Northridge, California 4/27/16
- Engaging Beneficiaries with Medicaid & Medicare & Long-Term Services & Supports: Strategic Approaches & Partnerships, Eugene, OR, 9/25/15
- CalOptima, Orange County 7/20-21/15
- Health Net, Southern California 3/10-12/15
- California Health and Wellness, Sacramento, CA 10/6-9/14

Access Barriers in Healthcare Clinics

L.A. County Coordinated Care Initiative, Quarterly Stakeholder Workgroup, 4/19/17 With: Randi Bardeaux, Personal Assistance Southern California, Chairperson Governing Board, Anastasia Bacigalupo, Executive Director, Westside Center for Independent Living and Paula Margeson, Executive Director, Dayle McIntosh Center

Care Coordination to Improve Health for High Need Members Across the Lifespan: Aging and Disability, Dual Eligibles Fall Forum, Oregon Health Authority, Salem, OR, 9/21/16

Physical Access Review Survey, California Facilities Site Review Training

- Los Angeles 1/7/16
- Sacramento 5/21/15

Disability Competent Services: Communication Access

Health Net Cultural and linguistic Services, Glendale, California, 12/9/15

Ensuring Effective Health Care for Seniors & People with Disabilities: Strategies for MMCOs & Provider:

For the California Department of Health Care Services, Sacramento 10/14/10 For Medical Managed Care Organizations:

- Oakland 1/19-10/11
- Los Angeles 1/26-27/11

Just Hop Up, Look Here, Listen Up, Stay Still and Hold Your Breath! Access to Medical Equipment - Where are We?

- Standards / Policies / Scooping / "Work-Arounds" Sutter Health, California 8/18/11, 9/16/11
- Japanese Society for Rehabilitation of Persons with Disabilities and National Institute of Population and Social Security Research, Tokyo, Japan, 12/3/10.
 Festival of International Conferences on Caregiving, Disability, Aging and Technology, Toronto, Canada 6/18/07
- ILRU Web Cast 1/4/07
- American Public Health Association, 134th Annual Meeting, Boston, MA. 11/7/06
- 2006 APRIL National Conference on Rural Independent Living, San Antonio, TX, 10/7-9/06/2006
- Southwest Conference on Disability, Albuquerque, NM, 10/4-6/06
- Audio Conference, Great Lakes ADA and Accessible IT Center, Chicago, IL, 8/16/05
- Pacific Rim Conference, Honolulu, Hawaii, 2/28/05
- California Foundation of independent living centers, Sacramento, California, 2/2/05
- State Independent Living Council, Woodland Hills, California, 10/26/04
- National Council on Independent Living, Annual Conference, Washington, DC. 6/04

Customize Your Customer Service: Welcoming People with Disabilities, L.A. Care, Los Angeles, CA 9/11/08

Life in the War Zone – Seeking Safe, Accessible, Effective, & Equivalent Health Care! Independent Medical Co-Op (IMCO), Orlando, FL. 5/5/08

Avoiding Killer Curbs by Building In Electronic Curb Cuts From The Beginning (Understanding the importance of electronic personal health records for persons with disabilities in accessing needed health care services.) American Public Health Association 2007 Annual Convention Special Invited Session: The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities: A Role for Health Informatics – Personal and Electronic Health Records, with Margaret Giannini, MD, FAAP, Saul Rosenberg, PhD, Brenda A. Leath, MHSA, 11/5/07 Washington, D.C.

Accessible Medical Equipment Survey Process, Sutter Health - California 10/11/07

Reflections on Taking Charge – Consumer Empowerment, Long Term Care Coalition San Diego, CA 9/12/07

Accessibility of Medical Equipment, Festival of International Conferences on Caregiving, Disability, Aging and Technology, Toronto, Canada, 6/18/07

E-Health – Cool Tools or More Barriers for People with Disabilities and Activity Limitations, Pacific Edge E-Health Innovations: Linking Research, Practice and Policy to Benefit Consumers & Communities, Kay Center – CGU Symposium, Pomona, CA, 12/1-2/06

Development of a Preventive Services Guide for Adults with Physical Disabilities Using Participatory Action Research, American Public Health Association, 134th Annual Meeting Boston, MA, 11/6/06

Quality Services for People with Disabilities & Activity Limitations

- Department of Managed Health Care, Sacramento, California 10/18/07
- California Department of Health Services, Medi-Cal Managed Care Division Quality Improvement Conference, "Partnering to Promote Quality" Sacramento, CA, 3/19/07
- Alameda Alliance for Health, Alameda, CA, 1/18-19/07
- Community Clinics L.A. Care Grantees, Los Angeles, CA, 1/17/07
- Health Net California Member Services, Sacramento 10/26-27/06, Woodland Hills, CA, 10/13 & 11/15/06

Strategies for Aging - What's Worked?

- Empowerment through Healthier Lifestyles, 2nd Statewide conference for Adults with Disabilities, Sponsored by the New York State Department of Health Disability and Health Program, Albany, NY, 9/19-20/06.
- Adults with Cerebral Palsy Conference, Rockville, MD, 10/19/05

People with Disabilities: Awareness & Business Implications, L.A. Care, Los Angeles, CA, 1/19-20/06

Accessibility Revisited: Policy-to-Practice, CARF's Business Practice Standards and "Hot Topics" Workshop Scottsdale, AZ, 12/8/03 & 12/5/05

Understanding Accessibility Elements of Facility Site Reviews

- Planned revisions and additions for the California Department of Health Care Services, Oakland, CA, 8/18/10
- Increasing Access and Quality of Care in Managed Care for Seniors and People with Disabilities Meeting, Sacramento, CA, 10/30/06
- L.A. Care, Los Angeles CA, 4/13/05, 4/29/05, 7/18/05
- Health Net, Woodland Hills, CA, 11/8/05

Developing Elements of Disability Literacy and Competency in Health Care Practice, L.A. Care, Los Angeles, CA, 9/6/05

Barriers to Effective Health Care for People with Disabilities, California Medical Board, Los Angeles, CA, with Brenda Premo, 2/17/05

Should We Mop The Floor, Or Fix The Roof? Public Policy and Health Research:

What is our role? Occupational Therapy Association of California, 28th Annual Conference, Pasadena, CA, with Brenda Premo, Erin Schwier & Brandi Buchanan, 11/6/04

How To Keep Running When There are No Trade-ins & Few Replacement Parts!

Partners on Wellness: Working Together to Promote Equality in Health Care for Women with Disabilities - Women with Disabilities Health Care Task Force, NJ Council on Developmental Disabilities, Statewide Conference, Princeton, NJ, May 2004

Making Managed Care Work For People With Disabilities

- California Association of Health Plans, The Future of Managed Care: Industry in Transition, Annual Conference, Rancho Mirage, California, with Brenda Premo, 10/12/04
- Local Health Plans of California, Sacramento, CA, with Brenda Premo, 9/8/04
- Western Center on Law and Poverty, Burbank, California, with Brenda Premo, and Janice Milligan, March 2004

Developing Elements of Disability Competency in Health Care Practice: Policy-to-Practice, Kaiser Permanente California Regional Offices, Pasadena and Oakland, CA, July – August 2003, February 2004

Developing Elements of Disability Competency in Health Care Practice, Inland Empire Health Plan, San Bernardino, CA, January 2004

Can Health and Disability Coexist? Select Summit on Disability and Health: A Call to Action, Des Moines, IA, November 2003

Disability Issues and Manages Care, RESPECT*ABILITY*, Disability Action & Advocacy Conference: Future of Disability Movement, Los Angeles, CA, October 2003

Developing a Communications Plan to Promote Osteoporosis Awareness -- Reaching the Harder to Reach Populations, National Osteoporosis Awareness Project, Oakland, CA. September 2003 with:

- Chaya Gordon American Society for Aging Moderator
- Linda Jackson National Caucus and Center on Black Aged, Inc., Representing African American Women
- Jyoti Rao National Asian Women's Health Organization Representing Asian Women
- Catherine Eng OnLok Representing the frail elderly
- Janet King Native American Health Center Representing Native American Women
- Mary Rosas Hispanas Organized for Political Equality Representing Latinas

Identifying Future Directions for Health and Wellness for Persons with Disabilities: NCIL Annual Conference, Washington, DC.with Tom Seekins, Ph.D., and Glen W. White, Ph.D., June 2003

Helping People with Disabilities Take Charge of Their Health Care at:

- & Keeping Your Body Out of the Shop! Access to Independence, San Diego CA, March 20008
- California Foundation of Independent Living Centers, City of Industr, CA, November 2002
- Health and Wellness Science Conference, Rehabilitation Research and Training Center on Health and Wellness, Washington D.C., March 2003, http://www.healthwellness.org/training/sciconf_briefs/helpingpeople.htm
- Dayle Macintosh Center, Anaheim, CA June 2003
- California Health Care Foundation in Oakland, CA July 2003
- Central Coast Center for Independent Living, Salinas, CA August 2003

The Intersection of Aging and Disability: Implications for Funders at Grantmakers in Aging Annual Conference, the Changing Face of America: Aging Realities in the 21st, October 2002, with Jeanne Argoff, Ph.D., Laura Mosqueda, M.D.

Preventive Health Screenings for Woman with Disabilities at NCIL Conference, Washington, D.C., June 2002, with Ann Musser D.O. and LeeAnne Carrothers PT, Ph.D.

Disability Forum, Healthy People 2010: Disability and Secondary Conditions at American Public Health Association (APHA) meetings. Atlanta, GA. October 2001

- Adult Mental Health and Participation—Kailes
- Data Issues—Vincent A. Campbell, Ph.D., Disability and Health Branch, Centers for Disease Control and Prevention, Atlanta, GA
- Childrens' Issues—Deborah Allen, Sc.D., Massachusetts Department of Public Health, Boston, MA
- Environmental and Technology Issues—David B. Gray, Ph.D., Washington University, St. Louis, MO
- State Disability and Health Issues and Plans—Norm White, M.AA, Kansas Department of Health and Environment, Topeka, KS

Disability & Health: Action Plans & Strategies for Keeping Our Bodies Out of the Shop at Women with Disabilities: Health Care Summit Strategies for Change, Iselin, New Jersey, Sponsored by NJ Developmental Disability Council, June 16, 2001

Bridging the Complaint Gap: Consumer - Provider Partnership at Living with Disability: New Treatment Approaches for the Practitioner, Cosponsored by Rehabilitation Institute of Chicago and Rehabilitation Research and Training Centers on Aging with Disability and Aging with Spinal Cord Injury, Chicago, Illinois. April 2001

Disability & Health a System Advocacy Agenda or Keeping Your Body out of the Shop at Disability & Health: a Wellness Agenda Conference Sponsored by Centers for Disease Control and Prevention and Michigan Association of Centers for Independent Living, Dearborn, MI, May 2000

Health, Wellness and Aging with Disability at:

- Santa Clara County Social Services Agency, CA. January 2001
- Center for Disability Issues and the Health Professions, Western University, Pomona, California, April 2000
- Funding all Women including Women and Girls with Disabilities sponsored by Grant Makers in Health, Oakland, CA June 1999

American Society on Aging Annual Meeting, San Diego, CA, March 2000

- Transformed Lives: Thriving with Disability with Brenda Premo, Amye Leong, and Pati Strong
- Aging with a Disability: Research Findings and Policy Implications for the Future with Bryan Kemp, PhD and Fernando Torres-Gil, MSW, PhD

NCIL Conference, Washington, D.C. June 1999

- Bridging the Great Divide between Independent Living and Healthcare...What is the role of an independent living center?
- Advocacy and Independent Living and Health Care: The Changing Paradigm

Consumer health-plan decision making and health-plan accountability with Robyn Stone, Charlotte Ducan, Bob Kafka, Gina McDonald, Bobby Silverstein, Peter Thomas at Empowerment in Managed Health Care: People with Disabilities in a Changing Health Care Environment, Houston, TX, March 1998

First International Conference on Aging with Disability Living with Disability: Exploring the Aging Process, San Diego, California, February 1998

- Maintaining Life Satisfaction while Aging with a Disability: Getting needs met and Public Policy Issues, with Joan Hedley, Carolyn Vash, and Bryan Kemp.
- Aging with Cerebral Palsy, with Margaret Turk, MD

Spinal Bifida Association of America, Annual Conference, Louisville, KY, June 1997

- Aging with a Disability
- Be a Savvy Health Care Consumer

NCIL Conference, Washington, D.C. June 1997

- Disability and Managed Care: Different Views on Advocacy Strategies. What Should Our Advocacy Strategies Be? Hear the Options and Join the Debate!
- Managed Care or Mangled Care What's Your Experience? What's Happening on the ILC Front?

The Savvy Health Care Consumer, Your Life May Depend on It!

- Abilities Expo, Long Beach, California, with Brenda Premo, June 2002
- NCIL Conference, Washington, D.C. June 1997
- Spinal Bifida Association of America, Annual Conference, Louisville, KY. June 1997
- Aging and Cerebral Palsy: A Vision for the Future, Toronto, Canada. May 1996

Our Future is Now! A Personal Perspective on Health at Aging and Cerebral Palsy: A Vision for the Future. Toronto, Canada. May 1996

Disability and Aging at University of California, Los Angeles, July 1996, February 1990

ARISE, Inc. 17th Annual Conference and Trade Show. Syracuse, NY. March 1996

- Mind & Body Finding a Balance
- How to Get What You Need From a Health Care Provider

Aging and Disability: Bridging the Gap! at Pennsylvania Statewide Conference on Independent Living, Harrisburg, PA, October 1995

Conversation on Disability Issues 2: Secondary Conditions and Aging with a Disability, Syracuse, NY. September 1995:

- Working Toward Health and Wellness for People with Disabilities, Model Interventions
- Where Does The Consumer Fit: Roles, Relationships and Responsibilities

Mid-Life Cripdom: Getting Fewer Miles per Gallon:

- Mega Super Conference on Disability Issues, Casper, WY, November 1997
- Pennsylvania Statewide Conference on Independent Living, Harrisburg, PA, October 1995
- Society for Disability Studies, Oakland, CA, June 1995
- President's Committee on Employment of People with Disabilities Annual Conference, Portland. OR, May 1995

Developing a Health Promotion Advocacy Agenda and Strategies at National Conference on Independent Living 1995 Conference and Annual Meeting, Bethesda, MD, May 1995

American Society on Aging Annual Meeting The Age Games, Who Plays? Who Wins? Atlanta, GA, March 1995:

- Aging Into the 21st Century: Women From Diverse Communities. Addressing the current and future concerns of women with disabilities of mid-life and older
- Researching Aging with Disability from a Life-course Perspective: Expanding the Game Plan to Include New Players

Turning 35 and Sometimes Feeling like 65! Aging with Disability - Where are we and what do we know?

Association of Independent Living Centers in New York Independent Living - Equal Opportunity: Fact or Fiction?, Albany, NY, November 1994

American Academy of Physical Medicine and Rehabilitation, Anaheim, CA, October 1994:

- Across the Lifespan: Adults with Cerebral Palsy and Spina Bifida
- Commonalities of Aging with Disability Across the Lifespan: Cerebral Palsy, Polio, Stroke, Spinal Cord Injury

Turning 35, Feeling Like 65 - What's Happening with Aging With Disability? at National Council on Independent Living Annual Meeting, Bethesda, MD, April 1994

Meeting the Challenges of Aging with Disability:

- USC School of Medicine, Los Angeles, CA, April 1994
- Rehabilitation Research and Training Center, at Rancho Los Amigos Medical Center, Long Beach, CA, March 1993

American Society on Aging, April 1990:

- Integration of Service Delivery
- Language and All Those Things That Unify and Divide
- Disability and the Life Course: A View From the Inside

Staying on Course, Aging With Disability at National Council on Disability's Conference for Families of People with Disabilities, Disability, A Family Affair, San Diego, CA, August 1989

The Economics of Effective Rehabilitation From the Consumer's Perspective and Implications of Disability Issues on Hospitals at American Hospital Association's Rehabilitation Division Conference, Los Angeles, CA, November 1987

Physical Access Review Survey, California Facilities Site Review Training, Los Angeles, CA, 1/7/16 & Sacramento, CA, 5/21/15

Professional Activities Disaster, Development of the Sendai Framework "Words into Action" Implementation Guide for Civil Society, Volunteers, Organized Voluntary Work and Community-based Organizations, December 2015 - present

LONG TERM CARE:

Long Term Care - A Unified Agenda for Those Who Are Aging and for Those Who Have Disabilities at San Francisco Bay Area's Conference on Long Term Care, Stanford University, Palo Alto, CA, August 1988

Future Impact of the Independent Living Movement on Disability Policy at Conference on Disability Policy: The State of the Nation, Washington, D.C., May 1987

Long Term Care Is an Independent Living Movement Issue at NCIL's Fifth Annual Conference on Independent Living, Washington, D.C., May 1987

Living with Long Term Disability at California Association for the Physically Handicapped Annual Conference, Los Angeles, CA, October 1985

University Course – Instructor, Disability Competency in the Health Professions - Spring 2002, Western University of Health Sciences, Pomona, CA - College of Allied Health Professions-Master of Science in Health Professions Education Program

HEALTH PROFESSIONAL ACTIVITIES

National Quality Forum Healthcare System Readiness Committee focused on developing a definition of healthcare system readiness, conduct an environmental scan of developed measures and measure concepts related to readiness, identify potential measurement proxies for readiness, and elicit multi-stakeholder input to prioritize measures, measure concepts, and measure gaps to inform future measure development and quality improvement efforts. 2018-2019

Center for Health Care Decisions, Doing What Works, Advisory Committee Statewide Work Group on Reducing Overuse of Ineffective or Unnecessary Medical Care to develop, initiate, monitor and evaluate approaches to reducing the overuse of selected unnecessary and wasteful medical services in CA. 2015-2016

California Collaborative for Long Term Services and Supports, 2013 – to present

Architectural and Transportation Compliance Board's Medical Diagnostic Equipment Advisory Committee, 2012 - 2014

Surgeon General's Call to Action to Improve The Health of People with Disabilities , 2006-2009

Work group to implement the goals and strategies contained in this report regarding health and wellness of people with disabilities www.surgeongeneral.gov

Committee of The Institute of Medicine (IOM) Of The National Academies Of Science "Disability In America: A New Look," 2005 – 2008

Builds on the 1991 IOM report Disability in America and the 1997 report Enabling America, the IOM committee reviewed progress and developments since the publication of those reports. The committee identified continuing gaps in disability science and proposes steps to strengthen the evidence base for public and private actions to reduce the impact of disability and related conditions on individuals and society in the United States

Rrectech: Rehabilitation Engineering Research Center On Recreational Technologies and Exercise Physiology Benefiting People With Disability National Advisory Panel, June 2003 - present

CARF - The Rehabilitation Accreditation Commission - Board, 1999 – 2005

Technical Expert Panel Supporting the Research Triangle Institute (RTI) and The Centers for Medicare & Medicaid Services (CMS) efforts to develop quality indicators for inpatient rehabilitation facilities, 2002 - 2003

Medical Rehabilitation Research, National Center for Medical Rehabilitation Research at the National Institute of Health - Advisory Board, 1998 - 2002

Public Interest Center on Long-Term Care - Board, 1992 – 1997

California Commission on Aging, Long-Term Care Committee (1985-1993)

California Department of Aging, Long-Term Care Committee (1990-1993)

National Institute on Disability Rehabilitation Research - Panel of Experts, 1991 - 1992

Deaf and Disabled Telecommunications Program - Administrative Committee Member, 1995 - 1997

California Commission on Aging - Long-term Care Committee, 1985 - 1993

Research and Training Center on Aging - Advisory Board, 1990 - 1993

ADVOCACY PUBLICATIONS

- 1. Kailes, J. (1984). "Disabled Community Infuriated by ACLU's Stand on Bouvia." New World For Persons With Disabilities
- 2. Kailes, J. (1987). Activists: Old, Young and In Between Must Get Their Act Together! New World for Persons With Disabilities. 14(1-Part One); 14(2-Part Two)
- 3. Kailes, J. (1987). "Developing New Disability Leadership." New World for Persons With Disabilities 13(11)
- 4. Kailes, J. (1988). "Politics and Power." Mainstream 13(5)
- 5. Kailes, J. (1988). <u>Putting Advocacy Rhetoric Into Practice: The Role of the Independent Living Center</u>. Houston, Independent Living Research Utilization (ILRU) Research and Training Center on Independent Living
- 6. Kailes, J. (1993). Advocacy: Reality or Rhetoric Inventory, Edition 11 9/99, Revised, 1995,1996, 1997,1999. KAILES Publications, jik@pacbell.net
- 7. Kailes, J. (1995). Beyond Oppression: Feeling the Movement and Its Power!, KAILES Publications, jik@pacbell.net
- 8. Kailes, J. (1997). The Ins & Outlines of Working With Elected Representatives, IL Net: NCIL/ILRU, 2323 S. Shepherd, Suite 1000, Houston, TX 77019

- 9. Kailes, J. (1997, 1998). Building and Maintaining Relationships with Elected Officials, KAILES Publications, jik@pacbell.net
- 10. Kailes, J. (1999). Bridging the Great Divide Independent Living and Health Care: Systems Change Strategies and Resources--Learning from the Trenches., ILRU Houston, TX, http://www.ilru.org/ilnet/ilnetbks.html
- 11. Kailes, J., Birster, Alice (1987). "Title 24: Our Access to Civil Rights." New World for Persons With Disabilities 14(4)
- 12. Kailes, J., Michaels, R. (1997). Taking Charge: Leadership and Systems Advocacy, ILRU Houston, TX, http://www.ilru.org/ilnet/ilnetbks.html.
- 13. Michaels, R., Kailes, J. (1996). Systems Advocacy: Beyond Rhetoric, ILRU Houston, TX, http://www.ilru.org/ilnet/ilnetbks.html
- 14. Shreve, M., Kailes, J. (1990). "The Right to Die of the Right to Community Support?" Midwest Medical Ethics 6(2& 3)
- 15. Premo, B., Kailes, J., & Richards, C. (2001). A Framework for Disability Public Policy in the 21st Century: Informed Choice and Consumer Empowerment: Defining, Refining & Reforming Services, American Rehabilitation Association, Switzer Seminars and monograph series, http://www.mswitzer.org/sem01/papers/premo.html
- 16. Kailes, J., (2008) <u>Community Organizing: Ground Rules for Grass Roots</u>
 <u>Organizers</u>, CENTER FOR INDEPENDENT LIVING Management Center
 & RRTC on independent living Management

ADVOCACY PRESENTATIONS

Advocacy Lessons learned from Independent Living in the United States Disabled Persons International, Tokyo, Japan, December 2010

Millenium Mission: Getting the Biggest Bang for That Buck! at Alliance for Technology Access Institute, Orlando, Florida, October 1999

ILNet National Teleconferences:

- Don't Toss Pebbles When You Can Launching Missiles Advocacy: Using the Internet Power Tools with Fred Fay, Patricia Yeager, Roland Sykes, David Newburger, March 1998
- So You Are Thinking of Launching a Web Site--Is It Worth the Investment? with June Kailes, Fern Moskowitz, Tony Sauer, Brian Hearn, Nancy Massey, Roland Sykes and Kathleen Kleinmann, September 1997

The Ins and Outs of Visiting the Hill at NCIL Annual Conference, Washington, D.C., June 1997

TAKING CHARGE, MAKING CHANGE, GETTING INVOLVED: Leadership and Systems Advocacy:

• Jasper, AL, September 1998

- Mega Super Conference on Disability Issues, Casper, WY, November 1997
- Tempe, AZ, ILNet, February 1997
- Atlanta. GA, ILNet, October 1996
- Reno, NV, ILNet, April 1996
- Utah Governor's Council For People with Disabilities, Salt Lake City, UT, November 1994

Systems Advocacy: Beyond Rhetoric at Vincennes, IN, September 1966

Standards and More: Beyond Compliance at Independent Living Technical Assistance Network, 1995: Portland, OR, July; Bethesda, MD, August; New Orleans, LA, September

Oppression at Pennsylvania Statewide Conference on Independent Living, Harrisburg, PA, October 1995

Self-Advocacy and Disability Pride:

- Cross-Disability Conference: United We Stand, Fargo, ND. September 1995
- Liberty Resources, Philadelphia, PA, May 1994
- Utah Governor's Council for Persons with Disabilities, Salt Lake City, UT, November 1994

Advocacy: ATA and Current Legislative Developments - How ATA can Initiate and Participate in Advocacy Efforts at Alliance for Technology Access Institute, French Lick, IN, August 1995

Squeaky Wheel Gets Greased...Getting Involved and Taking Charge at Aging and Long Term Care Network Conference, Santa Barbara County, CA, October 1994

Advocacy Skill Building Workshops:

- Austin, TX, February 1991 1994
- Santa Monica, CA, March 1991
- Philadelphia, PA, April & October 1990, May 1994
- Lansing, MI, May 1990

Association of Independent Living Centers In New York (AILCNY) Annual Conference, Albany, NY:

- Marketing as an Advocacy Tool, November 1991
- Are Independent Living Centers Becoming Mental Health Clinics? November 1989
- Law and Disability: Issues of Independence, October 1988 & November 1989
- Balancing Services and Advocacy The Debate Continues, October 1988 & November 1989

• How To Make Advocacy Work in Your ILC, October 1987

Leadership Development at Cornell University, Human Services Administration Program, (series of three-day regional workshops):

- Nashua, NH, April 1992
- Kansas City, KS, July 1992
- Denver, CO, August 1992

Leadership Development: Mentoring a Model for Success at United Cerebral Palsy Association Teleconference, October 1991

Getting Beyond Curb Cuts at Third Southeastern "Touch the Future Conference, Atlanta, GA, April 1991

Putting Muscle in Independent Living Center Advocacy Efforts at Keynote Speaker at Region V Independent Living Conference, Rochester, MN, October 1990

Advocacy and Independent Living Centers - We Got Trouble in River City! at Keynote Speaker at Colorado Statewide Conference on Independent Living, Greeley, CO, September 1989

Getting Involved in Disability Issues at National Lawyers Guild Conference, Los Angeles, CA, June 1989

Legislative Update on Housing at NCIL's Sixth Annual Conference on Independent Living, Washington, D.C., May 1988

Developing New Grass Roots Leadership at NCIL's Third Annual Conference on Independent Living, Kansas City, KS, June 1985

Public Policy Issues Affecting Independent Living at National Council on Disability, San Francisco, CA, April 1985

Elizabeth Bouvia and ACLU, as Seen by the Disabled Community at St. John's Hospital Ethics Committee, Santa Monica, CA, March 1984

Los Angeles' Minority Majority: Crystallizing a Public Relations Partnership at Public Relations Society of America, Los Angeles, CA, April 1983

Homeless Crisis for People With Disabilities at City of Santa Monica, CA, January 1983

Emergence of People With Disabilities in the Media at Annenberg School of Communications, University of Southern California (USC), Los Angeles, CA, December 1981

Who Defines Disability? at Daniel Freeman Hospital Comprehensive Resource Center, Inglewood, CA, July 1981

Universal Design:

7 Principles of Universal Design at Ed Roberts Campus Planning Meeting, Berkeley, CA, November 2001

Planning With Diverse Populations at American Planners' Association National Planning Conference, San Francisco, CA, April 1994

Designing for Independent Living: Issues from the Field at Center for Accessible Housing's Institute on Housing Accessibility Issues, Raleigh, NC, June 1991

Business Perspective: Developing Positive Customer and Employee Value at Association of Independent Living Centers In New York (AILCNY) Annual Conference, Albany, NY, November 1990

Advocating for Barrier Free Design:

- Region V Independent Living Conference Rochester, MN. October 1990
- Third Annual Japan-USA Conference on People with Disabilities, Yokohama, Japan, August 1989

Universal Design: Need and Opportunity for the '90s at Keynote Address - Remodeling for Accessibility, People and Profit. Cincinnati and Columbus, OH, November 1989

Barrier Free Design: An Environment Everyone Can Use at City of Santa Monica, CA, November 1987

AMERICANS WITH DISABILITIES ACT PUBLICATIONS

- 1. Kailes, J. (1992). American With Disabilities Act: Questions and Answers on Employment, Dayle McIntosh Center, 13272 Garden Grove Boulevard, Garden Grove, CA 92843, (714) 621-3300, (714) 663-2087 TDD
- 2. Kailes, J. (1993). ADA Videos, KAILES Publications, 6201 Ocean Front Walk, Suite 2, Playa del Rey, CA 90293, http://www.jik.com/resource.html, jik@pacbell.net
- 3. Kailes, J. (1994). Americans With Disabilities Act Compliance Guide For Food And Shelter Programs, http://www.jik.com/resource.html, jik@pacbell.net and The Los Angeles Emergency Food and Shelter Program Local Board
- 4. Kailes, J. (1994). Americans With Disabilities Act Compliance Guide For NonProfit Organizations, http://www.jik.com/resource.html, jik@pacbell.net

5. Kailes, J. (2000). Ten years after the ADA, accessibility remains elusive, CARF Connection, 4891 East Grant Road, Tucson, AZ 85712, http://www.carf.org/Dec00-CARFConnection/Dec2000Contents.htm

AMERICANS WITH DISABILITIES ACT PRESENTATIONS

What Makes a Meeting Accessible? Great Lakes ADA and Accessible IT Center, Audio Conference Series, August, 2004

ADA Requirements for Organizations:

- Access Facilities and Program Awareness, Technology and People with Disabilities, Los Angeles, March 2002
- Aids Project Los Angeles November 2001
- City of Santa Monica Grantees, July 2001

Ten Years after the ADA Lessons, Dilemmas, and Opportunities, with Jim McBain Henry Moss, Laura Solano, and George Terrien, at Build Boston, MA, November 2000

Complex Issues in Implementing the ADA: Planning Barrier Free Meetings, at California State University, Statewide Disabled Employment Program, Los Angeles, CA, October 1997

Customer Issues and Disability Diversity at Shell Oil, San Francisco, CA, September 1997

ADA Implementation in Public Schools

1995: Providence, RI and Middleton, CN. April Denver, CO; June Atlanta, GA; July Oakland, CA; August Chicago, IL

Evaluating for Compliance: Tips for Getting It Done, Title II

- City of Santa Monica, Grantees, CA, March 1995
- ADA Training Conference sponsored by California Department of Rehabilitation and Disabled in State Service, Sacramento. October 1994

Toward Access and Opportunity: A VIP Workshop on Title I of the ADA at California State University, Long Beach, 1995: January; 1994: November, October, April

ADA Accessibility Training for LA Regional Family Planning ClinicsCalifornia 1994: Los Angeles, March (4 trainings); San Diego, July; Oakland, October

Update of the ADA at Center for Nonprofit Management Executive Round Table, Los Angeles, CA, October 1993

Implementing ADA at USAir, Dayton, OH, October 1993

ADA's Employment Provisions for Classified Managers at Santa Monica College, CA, June 1993

Marketing Your Center's ADA Services at California Foundation of Independent Living Centers, Sacramento and Newport Beach, January and September 1993

Technical Assistance for Employers at the California Governor's Committee for Employment of People with Disabilities, Anaheim, CA, October 1992

How ADA Can Work for You: A New Form of Advocacy Power Assist at Arthritis Foundation, Los Angeles, CA, September 1992

Training for ADA Trainers and Consultants at California Foundation of Independent Living Centers, Los Angeles and Berkeley, CA, March 1992

Barrier Free Meetings: Keeping Up with a Moving Target at Association of Independent Living Centers in New York, Albany, November 1992

AMERICANS WITH DISABILITIES PROFESSIONAL ACTIVITIES

Pacific Disability and Business Accommodations Center - Advisory Board (1992 – 2002)

INDEPENDENT LIVING PUBLICATIONS

- 1. Brown, S., Gonzalez, L. Kailes, J. (1997). For the Crime of Being Different: Exploring Disability Rights, History, Philosophy, and Culture, ILRU Houston, TX, http://www.ilru.org/ilnet/ilnetbks.html
- 2. Kailes, J. (1985). "Independent Living Centers." Long-Term Care Reporter 1(3)
- 3. Kailes, J. (1985). People with Disabilities and the Independent Living Model. Case Management in Human Service Practice. M. Weil, Karls, J, Jossey-Bass
- 4. Kailes, J., Roy, K., Elias, G. (1991). The Reauthorization of The Rehabilitation Act, A report to the President and to Congress of the United States, National council on Disability, 1331 F St., NW, Suite 850 Washington, D.C. 2000, Voice: (202) 272-2004, TTY: (202) 272-2074: 58
- 5. Kailes, J. (1993). <u>Disability Pride</u>: <u>The Interrelationship of Self-Worth, Self-Empowerment, and Disability Pride</u>. Houston, Independent Living Research Utilization (ILRU) Research and Training Center on Independent Living.
- 6. Kailes, J. (1997). Centers for Independent Living, KAILES Publications, jik@pacbell.net
- 7. Kailes, J. (1997). Independent Living Philosophy and Practice (Two cassette tapes), KAILES Publications, jik@pacbell.net
- 8. Kailes, J. (1997). Independent Living: Reality or Rhetoric Inventory, KAILES Publications, jik@pacbell.net

- 9. Kailes, J. (1997). So You Are Thinking of Launching a Web Site--Is It Worth the Investment?, ILRU Houston, TX, http://www.ilru.org/ilnet/ilnetbks.html
- 10. Kailes, J., Shreve, M (1993). Training for ADA Trainers and Consultants, Kailes-Publications, 6201 Ocean Front Walk, Suite 2, Playa del Rey, California 90293-7556, http://www.jik.com/resource.html, jik@pacbell.net
- 11. Kailes, J., Shreve, M. (1993). Marketing Your Center's ADA Services Two Training Workshops. Long Beach, Kailes-Publications, 6201 Ocean Front Walk, Suite 2, Playa del Rey, California 90293-7556, http://www.jik.com/resource.html, jik@pacbell.net
- 12. Michaels, R., Kailes, J. (1994). Independent Living and the Rehab Act, ILRU Houston, TX, http://www.ilru.org/ilnet/ilnetbks.html
- 13. Michaels, R., Kailes, J., McDonald, G., Spooner, P., Jordan, H., Sykes, R., Richards, L., Dresden, C., Heinsohn, D., Kemp-Moye, D., Martinez, M., Smith, Q., and Hughey, A.M. (1995). Standards & More: Beyond Compliance--Addressing Independent Living Needs of Today & Tomorrow
- 14. Michaels, R., Kailes, J., Shreve, M., Richards, L., Dresden, C., Heinsohn, D., Smith, Q., Telsford, D., and Hughey, A. M. (1994). Standards & More: Beyond Compliance

INDEPENDENT LIVING PRESENTATIONS

Independent Living in the USA Trends and the Future Directions, Japan Association of Independent Living, Tokyo November 2010

Online Courses: Introduction to Independent Living Philosophy, 2/15-4/4/99, 6/19-7/21/01, 1/21-2/8/02, 3/22-4/9/04, ILRU, University of Northern Colorado, and Utah State University

Millennium Mission: Getting the Biggest Bang for That Buck! at ILNet Leadership Training, Houston, TX. November 1999

A Renewal of Spirit: Back to Our Roots (Getting on the Same Page) at Anchorage, AK,October 1997

The Evolution of Independent Living at Abilities Exposition, Anaheim, CA, May 1997

IL Philosophy Training: What's Cutting Edge? What's Working? at NCIL Conference, Washington, D.C., June 1997

A Renewal of Spirit, Back to Our Roots, Getting on the Same Page, Independent Living Philosophy and Practice

- Berkeley, CA, February 1997
- Santa Barbara, CA, January, February 1997

Increasing Effectiveness of a Board of Directors at Alliance for Technology Access Institute, French Lick, IN, July 1995

Improving Service Systems for People with Disabilities: Findings from a Four-Year RWJF Demonstration in Eleven Sites at Society for Disability Studies, Oakland, CA, June 1995

Independent Living and The Rehabilitation Act, 1994: Atlanta, GA - February; Albany, NY - May; Bethesda, MA - June; Chicago, IL & Portland, OR - July; Los Angeles, CA - September

Philosophy Forum:

- South Central Los Angeles, CA, (3 trainings). April 1994
- Independent Living Resources, Pleasant Hill, CA, June 1993
- Independent Living Resources Center, Santa Barbara, CA, August 1993
- Kansas Association of Independent Living Centers, Topeka., KS, May 1991
- Region V Continuing Education Program (RCEP) meeting for Illinois Independent Living Centers, Chicago, IL, July 1991
- United Cerebral Palsy of Indiana Annual Meeting, Indianapolis, IN, March 1987
- Santa Monica Westside Community Services Council, CA, September 1983

Disabilities in the Workplace at Keynote address at Aspirations for Tomorrow presented by ARISE, Inc., Syracuse, NY. March 1990

Options for Living Independently at Keynote Speaker at Independent Living and Peer Counseling Conference, Saporro, Japan, August 1989

Overview: Independent Living Centers in the USA at Third Annual Japan-USA Conference on People with Disabilities, Yokohama, Japan, August 1989

A Comprehensive Look at Independent Living Centers' Evaluation and Standards, Past and Future at NCIL's Third Annual Conference on Independent Living, Kansas City, KS, June 1985

The Use of Computers in Independent Living Centers at Regional Rehabilitation Network Conference, Los Angeles, CA, February 1985

The Role of the Social Worker in an Independent Living Center at Beyond Survival, A Conference on Independent Living, Denver, CO, August 1983

The Future of Independent Living Centers in the USA at Abilities Unlimited Conference, Los Angeles, CA, March 1983

Unique Choices within the Final Phase of Rehabilitation at Second Annual International Conference on Comprehensive Rehabilitation and Independent Living, Los Angeles, CA, April 1982

Sexuality and People with Disabilities at 21st Annual Institute for Social Workers in Clinical Practice, Los Angeles, CA, February 1982

Independent Living Centers as Adjuncts to Traditional Rehabilitation Services at International Conference on Comprehensive Rehabilitation and Independent Living, Los Angeles, CA, April 1981

Coalitions for Improving Services to Adolescents With Disabilities at New Otani Hotel, Los Angeles, CA, April 1981

Myths - Disability and the Classroom at Santa Monica College, CA, March 1981

Online University Courses: Introduction to Independent Living Philosophy - University of Northern Colorado and ILRU

- 2/15-4/04/99
- 6/19-7/21/00
- 7/16-8/03/01
- 1/21-2/08/02

INDEPENDENT LIVING PROFESSIONAL ACTIVITIES

• National Council of Independent Living (NCIL)

Elected Offices:

- Board, 1983 1989
- Acting President 1988
- Internal Vice President 1987 1988
- External Vice President 1985 1987
- Board member at Large 1983 1985

Committees:

Staffed: Telecommunications Network 1991 - 1992

Chaired:

- Housing Advocacy 1988 1990
- Legislation and Advocacy 1987 1988
- Technical Assistance 1986 1988
- Standards and Evaluation 1983 1986

Member:

- Telecommunications Network 1992 1996
- Fund Raising 1987 1989
- Health 1993 1995 and 1998

- Rehabilitation Act 1989 1995
- National Conference 1994 1995, and 1997 1999
- California Foundation for Independent Living, member (1982-1989)
 - Elected Offices: President, Vice President, Treasurer and Secretary.
 Committees:

Chaired:

- Technical Assistance and Planning 1983 1987
- Finance 1985 1986
- o Member: Standards and Evaluation Peer Review 1985 1987
- World Institute on Disability, Board Member (2000-2004)
- Alliance Technology Access, Board Member (1994 2004)
- Adaptive Environments, Board Member (1993-1997)
- National Telecommunications Blue Ribbon Panel Member, 1991 1994
- Research And Training Center On Public Policy And Independent Living -Advisory Board, 1990 - 1996
- Assistive Technology And Home Modification Advisory Group for American Society on Aging, 1995 - 1997
- City Of Santa Monica Building And Safety Commission Commissioner, Access Division, 1994 1996
- Coro-City Focus Public Affairs Training Program 1989 1990
- Region Ix, Regional Rehabilitation Network Advisory Panel Member, 1985 -1987
- Office Of Special Education And Rehabilitation Services Administration -(OSERS) Independent Living Standards and Evaluation Advisory Committee, 1984 – 1987

DISABILITY COMPETENCIES PUBLICATIONS

- 1. Apodaca, M., Watson & Kailes, J (1985). "A Sociometric Comparison of Mainstreamed, Orthopedically Handicapped High School Students and Non-Handicapped Classmates." Psychology in the Schools 22: 95-101
- 2. Kailes, J. (1984). Language is More Than a Trivial Concern, Edition 9, Revised 1988, 1990, 1992, 1993, 1995, 1997, 1998, 1999. KAILES Publications, jik@pacbell.net
- 3. Kailes, J. (1986). Portraying People with disabilities: Guidelines for the Media and Entertainment Industry, in Options, Westside Center for Independent Living, 12901 Venice Boulevard, Los Angeles, CA 90066. 10
- 4. Kailes, J. (1987). Barrier Free Design: An Environment Everyone Can Use. Santa Monica Evening Outlook
- 5. Kailes, J. (1989). "Barrier Free Design Can Improve Your Profits in Multiple Ways." Worklife 2(3)
- 6. Kailes, J. (1990). <u>Barrier Free Design Benefits All, Not Just Disabled</u>. Los Angeles Times: K17-K18

- 7. Kailes, J. (1990). Language Is More Than a Trivial Concern. Paralyzed Veterans of America Bulletin, Virginia Chapter
- 8. Kailes, J. (1991). Preferred Practices to Keep in Mind as You Meet People with Disabilities, Edition 2002, Revised: 1992, 1993, 1995, 1997, 1998, 2000, 2001, 2002. KAILES Publications, jik@pacbell.net
- 9. Kailes, J. (1993). Accessibility Guidelines for Speakers, Edition III-July 2000, KAILES Publications, jik@pacbell.net
- 10. Kailes, J. (1993). Offering Access to Customers with Disabilities Expands Market Share, KAILES Publications, jik@pacbell.net
- 11. Kailes, J., Jones, D. (1993). A Guide to Planning Accessible Meetings, KAILES Publications, jik@pacbell.net & ILRU Houston, TX, http://www.ilru.org/ilnet/ilnetbks.html
- 12. Kailes, J. (1997, 1998). Accessibility Checklist for Events and Meetings, Edition 1.1, KAILES Publications, jik@pacbell.net
- 13. Kailes, J. (2000). "The Language of Disability, Humanism in the Health Sciences." Western University of Health Services 4(1): 10-1.
- 14. Kailes, J., Holland, R., Lester, M., Brown, S. (2001). Access Aware: Extending Your Reach to People with Disabilities, Alliance for Technology Access, 2175 E Francisco Blvd., Suite L, San Rafael, CA 9490, ATAinfo@ATAccess.org, 415.455.4575, TTY 415.455.0491 http://www.ataccess.org
- 15. Kailes, J. (2002). Who Are People With Disabilities and Activity Limitations?, Kailes-Publications, 6201 Ocean Front Walk, Suite 2, Playa del Rey, California 90293-7556, http://www.jik.com/resource.html, jik@pacbell.net.
- 16. Morales, T., Holland, R., Lester, M., Kailes, J. (2002). Starting Points, Alliance for Technology Access, 2175 East Francisco Blvd., Suite L, San Rafael, CA 94901, Voice: 415-455-4575, TTY: 415-455-0491, ATAinfo@ATAccess.org, http://www.ATAccess.org
- 17. Kailes, J.I. 2015. Accessibility Guidelines for Presenters, Edition IV July 2015, in Mid-Atlantic ADA Center and TransCen Inc., <u>Accessible Meetings</u>, Events, and Conferences Guide.

DISABILITY COMPETENCIES PRESENTATIONS

Customer Services for People with Disabilities at American Public Health Association & Boston Convention and Visitor Service Bureau, MA, November 2000

Welcoming Visitors with Disabilities, J. Paul Getty Museum - Volunteer and Visitor Services Departments, Los Angeles, CA. 1998-Present, and Community Technology Fund, Los Angeles, CA, September 2000

TECHNOLOGY & TELECOMMUNICATIONS PRESENTATIONS

ATT's Telecommunication Citizens Advisory Panel - (Formerly) SBC's and Pacific Bell's - 1996 - 2007, Chair, 1999

National Conference of the President's Committee on Employment of People with Disabilities, New Orleans, LA, May 1998

- Ensuring Access to Technology in the 21st Century with Jamal Mazrui, and Moira Shea
- How Section 255 of the Telecommunications Act of 1996 Will Impact on the Workplace for People with Disabilities with Susan K. Palmer, Jeffrey D. Pledger, Jennifer J. Simpson and Dan Phythyon

Cyber Marketing: So You Think You Need a Web Site? NCIL Conference, Washington, D.C., June 1997

Accessibility Guidelines for Telecommunications Equipment: What's Next? at Technology and People with Disabilities Conference, Los Angeles, CA, March 1997

Information Access Solutions at NCIL 1996 Annual Conference & Meeting, Washington, D.C., May 1996

Technology and Getting off the Curb: Funding for Assistive Technology at Touch the Future, Third Southeast Regional Conference on Technology, Atlanta, GA, April 1991

Meaningful, Significant, Responsible Consumer Involvement at Utah Assistive Technology Project - Staff and Volunteers, Salt Lake City, UT, November 1990

Funding Technology at RESNA's Technical Assistance Project Workshop on Funding, Washington D.C., March 1990

Making Disability and Cultural Diversity a Priority at Community Technology Fund of California, Los Angeles, September 2000

Models for Success: Advancing the Goals of Section 255, with Jacquelyn Brand, Andrew Imparato, Susan Palmer, Paul Schroeder, Claude Stout, Jim Tobias, and Andrea Williams, at Alliance for Public Technology, Washington, D.C., September 2000

Telecommunications and Advocacy: Playing Hardball with the Team. with Mary Lester and Russ Holland at Alliance for Technology Access, Annual Institute, Nashville, TN, July 27 1997

Technology and Persons with Disabilities Conference sponsored by the Center on Disabilities, California State University - Northridge, Los Angeles, CA

- Section 255, Telecommunications Act of 1996, 1997, 1998
- Will the National Information Infrastructure be Accessible? 1994
- Computer Bulletin Board Systems on Disability Information 1994

Technologies of Freedom: Bringing Home the Electronic Highway at Alliance for Public Technology, Washington, D.C., February 1994

Using Computer Networks for Beginners and Seasoned Users: Getting Your Dime's Worth:

- Independent Living Technical Assistance Network, 1995: Portland, OR, July; Bethesda, MD, August; New Orleans, LA, September
- Leadership in Technology Management, CA, 1995: Oakland, May; Los Angeles, 1995; 1994: San Francisco, August and September; Los Angeles, July
- Cross-Disability Conference: United We Stand, Fargo, ND. September 1995
- California Assistive Technology Systems Steering Council, San Francisco, CA, June 1994
- National Council on Independent Living Annual Meeting, Washington, D.C. May 1991 & 1992; ILRU, Houston, TX, September 1992
- Board of Directors, Oakland, CA, March & October 1992
- California Foundation of Independent Living Centers, Berkeley and Anaheim, CA, May 1991
- Association of Independent Living Centers in New York, Albany. November 1991

The Vital Role of Computer Networking in the 21st Century:

- Independent Living and 21st Century, Oakland, CA, October 1991
- Association of Independent Living Centers in New York (AILCNY) Annual Conference, Albany, NY, November 1991

TECHNOLOGY AND TELECOMMUNICATIONS PROFESSIONAL ACTIVITIES

- National Council On Disability Tech Watch Task Force Member (1995 2007)
 - Summit Participant 1996
 - o Advisory Committee (1984 1990)
- **Deaf and Disabled Telecommunications Program** Administrative Committee Member, 1995 1997
- World Institute on Disability's National Telecommunications Blue Ribbon Panel Member, 1991 1994
- ATT's TELECOMMUNICATION CITIZENS ADVISORY PANEL (formerly) SBC's and PACIFIC BELL'S 1996 2007, Chair, 1999
- Access Board's Telecommunication Access Advisory Committee (June 1996 March 1997)

MISCELLANEOUS PROFESSIONAL ACTIVITIES

- National Council of Independent Living (NCIL)
 - **Elected Offices**:
 - Board, 1983 1989
 - Acting President 1988
 - Internal Vice President 1987 1988
 - External Vice President 1985 1987
 - Board member at Large 1983 1985

Committees:

Staffed: Telecommunications Network 1991 - 1992

Chaired:

- Housing Advocacy 1988 1990
- Legislation and Advocacy 1987 1988
- Technical Assistance 1986 1988
- Standards and Evaluation 1983 1986

Member:

- Telecommunications Network 1992 1996
- Fund Raising 1987 1989
- Health 1993 1995 and 1998
- Rehabilitation Act 1989 1995
- National Conference 1994 1995, and 1997 1999
- California Foundation for Independent Living, member (1982-1989)
 - Elected Offices: President, Vice President, Treasurer and Secretary.
 Committees:

Chaired:

- Technical Assistance and Planning 1983 1987
- Finance 1985 1986
- o Member: Standards and Evaluation Peer Review 1985 1987
- California Commission on Aging, Long-Term Care Committee (1985-1993)
- California Department of Aging, Long-Term Care Committee (1990-1993)
- World Institute on Disability, Board Member (2000-2004)
- Alliance Technology Access, Board Member (1994 2004)
- Adaptive Environments, Board Member (1993-1997)
- Pacific Disability and Business Accommodations Center Advisory Board (1992 2002)
- National Council On Disability Tech Watch Task Force Member (1995 2007)
 - o Summit Participant 1996
 - o Advisory Committee (1984 1990)
- National Institute On Disability Rehabilitation Research Panel of Experts, 1991 1992

- Research and Training Center On Public Policy And Independent Living -Advisory Board, 1990 - 1996
- Assistive Technology And Home Modification Advisory Group for American Society on Aging, 1995 1997
- City Of Santa Monica Building And Safety Commission Commissioner, Access Division, 1994 1996
- Coro-City Focus Public Affairs Training Program 1989 1990
- California Commission On Aging Long-term Care Committee, 1985 1993
- Research And Training Center On Aging Advisory Board, 1990 1993
- California Department Of Aging -Long-term Care Committee, 1990 1993
- Region Ix, Regional Rehabilitation Network Advisory Panel Member, 1985 1987
- Office Of Special Education And Rehabilitation Services Administration -(OSERS) Independent Living Standards and Evaluation Advisory Committee, 1984 – 1987

AWARDS

- American Public Health Association's Allan Meyers award "for combined excellence across the areas of research, teaching, and advocacy to improve the health and quality-of-life for people with disabilities." November 12, 2018
- Doug Martin Award of Excellence for "visionary leadership in conceiving, promoting and moving emergency services from a vague "special needs "focus to functional planning, response and recovery thus making a tangible change emergency in responsiveness for people with disabilities." July 28, 2018
- City of Los Angeles Appreciation "for relentless pursuit to do good and unwavering dedication to the disabled community and hard work resulting in lasting impacts that touch the lives of many." July 28, 2018
- National Council on Independent Living "Lifetime Achievement Award for "decades off hard work and leadership to advance the Independent Living and Disability Rights Movement and her commitment to promoting the civil and human rights of people with disabilities," July 16, 2011
- <u>Cathleen Lyle Murray Award</u> recognizes "outstanding individuals in non-medical professions on the basis of their impact on society through their humanitarian efforts to enhance the lives of persons with disabilities." Awarded by The American Academy for Cerebral Palsy and Development Medicine at the 63rd Annual Meeting September 23-26, 2009
- Appreciation from the Los Angeles City Council for sharing extensive experience on disability policy that made the new Del Rey Lagoon Playground Equipment accessible to more families and children. Presented by Bill Rosendahl, Councilmember 11th District, April 4, 2009

- Outstanding contributions and advocacy on behalf of people with disabilities, National Association of Rehabilitation and Research Training Centers, April 25, 2005
- Outstanding service and dedication 1995-2002, United States Access Board -2003
- Honorary lifetime membership in The Association of Access Engineering Specialists for outstanding leadership and skillful contribution in the field of accessibility - 1999
- Westside Center for Independent Living's "Founders Award" for vision, leadership and advancing the rights and opportunities of people with disabilities -1997
- Recognition from the California Department of Rehabilitation for participation in the development of a Strategic Plan for Assistive Technology for People with Disabilities - 1992
- Mary E. Switzer Scholar presented by the National Rehabilitation Association for excellence and accomplishments in service to people with disabilities 1991
- Americans With Disabilities Act Award presented by the Task Force on the Rights and Empowerment for People with Disabilities for outstanding contributions to the enactment of the World's First Comprehensive Civil Rights Law for People with Disabilities 1990
- Westside Center for Independent Living "Award" for excellence in the pursuit of a just and barrier-society 1990
- Recognition from the California Legislature for dedicated service as Executive Director of the Westside Center for Independent Living - 1989
- Appreciation from the City of Los Angeles for 25 years of Community Action and exemplary efforts and accomplishments of great value to the community, presented by Gilbert Lindsey, Councilmember 9th District - 1989
- Westside Pilot International, Handicapped Professional Woman of the Year -1988
- Weinberg Chai Award for enhancement of the quality of Jewish Life, by the Jewish Federation Council, Los Angeles for Co-chairing a very successful "Conference on the Concerns of Jews with Disabilities" - 1983
- Woman of the Year Award, presented by Santa Monica YWCA 1982
- Distinguished Alumna Award, presented by the University of Southern California Graduate School of Social Work - 1980